

Correlation of family function and the quality of life of young adults with chronically-ill siblings

Aezrile A. Ignacio, Kimberly T. Huplo, RN, Danielle Camille A. Ignacio, Shari L. Guerra, Vanessa Angelica D. Gulla, Alain Francis A. Guloy, Erickson P. Gudelano III, Alayssa Katrina Marie P. Ilagan, RN, Ada Marielle B. Ignacio, RMT, Micah Raphaela C. Guerrero, Camille Mariz P. Guerrero, John Adrian Gelino M. Guibone, and Maria Teresa S. Tolosa, MD, DClínEp

Abstract

Introduction Chronically-ill patients are known to pose an impact on the family function (FF) and quality of life (QoL) of their family caregivers and pediatric siblings. However, there is limited literature on the relationship between FF and QoL. This study aimed to determine the correlation of FF and QoL among healthy young adults with siblings with chronic diseases.

Methods This was an analytical cross-sectional study among young adults, selected by purposive sampling, with chronically-ill siblings. The CAPGAR and WHOQOL-BREF questionnaires were used for data collection. Spearman's correlation coefficient r was used to determine the correlation between FF and QoL.

Results More than half (53.9%) of the respondents had highly functional families. Majority of the participants (66.5%) had fair QoL. There was a weak but significant positive correlation ($r = 0.27$, $p < 0.001$) between FF and QoL.

Conclusion There is a weak but significant positive correlation between family function and quality of life among healthy young adults with a sibling suffering from a chronic debilitating illness.

Keywords: Sibling, chronically-ill, family function, quality of life

The presence of a chronically-ill family member may result in emotional burdens and stress which greatly impacts not just the family caregiver's quality of life, but also the siblings'.¹⁻⁶ Recent studies have shown the impact of chronically-ill patients on their siblings, as the healthy children may feel "forgotten" by their parents - contributing to an increased risk of depression and anxiety.^{2,5,7} The effects of chronically-ill patients on their siblings may pose great psychosocial

risks and physical health strain due to the close influence that they have on each other.^{6,8}

Family function is an essential factor which affects the quality of life of an individual. To date, there has been limited research investigating the correlation of the family function (FF) and quality of life (QoL) among healthy young adults with chronically-ill siblings. The objective of this study was to determine the correlation of FF and the QoL among healthy young adults with siblings suffering from chronic debilitating diseases. The research may provide data to serve as a basis in formulating policies to protect and develop sensitivity for healthy young adults with a chronically-ill sibling and increase awareness of the possible problems among them. The relationship covers the young adult's perception of himself, dynamics with his sibling with chronic disease, parents, peers, and other people in the society;

Correspondence:

Maria Teresa S. Tolosa, MD, DClínEpi, Department of Preventive and Community Medicine, College of Medicine, University of the East Ramon Magsaysay Memorial Medical Center, Inc., 64 Aurora Boulevard, Barangay Doña Imelda, Quezon City, PH 1113; email: mstolosa@uerm.edu.ph

relevant research can provide information to families with chronically-ill members, researchers, and medical professionals on the aspects of the young adult's life which may need intervention.

Methods

This analytical cross-sectional study was conducted after being approved by the Ethics Review Committee of UERMMMCI. It included healthy young adults aged 18 to 35 years, who had siblings clinically-diagnosed with a debilitating non-communicable disease necessitating close monitoring and supervision. Participants and the chronically-ill sibling should have been living together for at least a year, with the latter residing or receiving treatment and care in a health facility within Quezon City. Participants were included if they were literate and provided written informed consent. Individuals who were unable to communicate, currently diagnosed with, or had a history of neurologic and psychiatric illness, currently treated with medications that might affect concentration, and those with adverse habits and drug abuse were excluded.

Purposive sampling was used to screen eligible participants who were sourced from barangays and health care service institutions in Quezon City. The area was chosen because this is where the most number of chronically-ill persons undergo therapy due to the presence of more advanced treatment facilities.⁹ The sample size of 341 respondents was computed based on the study of Rodriguez-Sanchez which showed that $32.3 \pm 5\%$ of caregivers had low quality of life, 0.05 significance and 99.99% power.¹⁰ An additional 20% were recruited as allowance for respondents with incomplete responses.

Participants answered either the Filipino or English version of the Comprehensive Family APGAR (CAPGAR) and WHO Quality of Life-BREF (WHOQOL-BREF) questionnaires in their primary care settings or in their homes following permission of a primary health facility or the assistance of focal barangay persons, respectively. The CAPGAR and WHOQOL-BREF questionnaires are generic instruments whose validity and reliability have been tested by the WHO and various researchers and the UP Philippine General Hospital's Department of Family and Community Medicine to be used as a standardized

tool to assess family function (FF) and quality of life (QoL), respectively.^{9,11,12} The data collection tool also included a section for respondents' demographics and characteristics.

The 15-item CAPGAR Scale was adapted from the Family APGAR questionnaire which is used to determine the function of the family and the ability to endure and adapt to the situation, based on adaptation, partnership, growth, affectation, and resolve.^{11,13,14} The CAPGAR includes three subscales representing three domains: flexibility (6 items), cohesion (6 items), and communication (6 items). It also has five items similar to those of the original Family APGAR.¹¹ This was scored as follows: 0-6, highly dysfunctional; 7-12, moderately dysfunctional; 13-18, functionally at risk; 19-24, moderately functional; and 25-30, highly functional.¹⁴ The CAPGAR questionnaire was created to provide a valid and reliable measure of family function among Filipinos.

The World Health Organization Quality of Life-BREF Instruments (WHOQOL-BREF), an abbreviated form of the WHOQOL-100, was used to assess the QoL profiles of the respondents.¹² The WHOQOL-BREF can be self-administered if the respondent has adequate knowledge, or interview-assisted if deemed necessary. The 26-item questionnaire includes overall QoL and general health (two items), plus 24 other items grouped under four domains: physical health (7), psychological (6), social relationships (3), and environment (8). The tool uses a five-point scale with 1 being the lowest and 5 being the highest.¹² The items were constructed in a Likert scale with five balanced responses such as very poor/dissatisfied (1), poor/dissatisfied (2), fair (3), good/satisfied (4), and very good/very satisfied (5). The raw total domain QoL score was arranged from poor (26-60), fair (61-95), and good (96-130), following the categorization method employed by Dajpratham.¹⁵ The raw scores were transformed to make them comparable to the WHOQOL-100.¹² The domain scores in the WHOQOL-BREF questionnaire were scaled in a positive direction: the higher the score, the higher the QoL. This also denoted the perception of an individual in a particular domain and aided in the correlation of the mean total transformed domain score against the total CAPGAR scores.

The CAPGAR score was correlated with the transformed WHOQOL-BREF score and tested using Spearman's correlation coefficient rho (r). This was

computed using SPSS Statistics 24.0 Software, with a p value of ≤ 0.05 set as significant. A scatter plot was produced to visualize the direction of the correlation. The processing of scatter plot and the organization and computation of demographic data were done using Microsoft Excel.

Results

A total of 409 individuals were recruited but 33 were excluded because of illness or non-completion of at least 80% of the WHOQOL-BREF questionnaire, leaving 376 respondents for analysis. Majority of the participants were female, with a mean age of 26 years; a third of them belonged to the 25-29-year-old bracket, as shown in Table 1. Half of the participants completed tertiary education. Most of them were in common-law relationships. More than half of the participants had no employment or regular activity, and the identified financial source of expenses was savings or salary in more than half of the respondents. The rest relied on family, spouse and children. Around 95% of the respondents denied any illness, while the rest assumed or felt that they had an undiagnosed disease.

Overall, half of the participants' siblings had neuropsychiatric problems (53.2%), followed by other major organ diseases (29.3%), cancer (10.1%), and PWD (7.4%), as shown in Table 1. Participants whose siblings had intellectual disability (22.1%) described the latter's condition as being or having any of the following: special child, Down syndrome, autism, global late development, and mental retardation; central nervous system disorders were seizures, epilepsy, dementia, stroke, hydrocephalus, meningitis, or cerebral palsy. Some respondents had siblings with a learning disability (i.e., hearing, visual, and speech impairment); other siblings had a psychiatric disorder (i.e., bipolar disorder, schizophrenia, clinical depression). Among the cardiovascular diseases, patent ductus arteriosus, patent foramen ovale and hypertension were mentioned. Endocrine diseases included goiter, hyperlipidemia, and diabetes; malignancies included leukemia, prostate and breast cancer. Physical disability was present as a congenital condition or a bilateral lower extremity amputation. Most of the participants (53.99%, 95% CI 48.90, 58.99%) had highly functional FF. Less than 5% had dysfunctional FF, as seen in Table 2. The untransformed

(raw) and transformed mean scores of QoL and its domains are presented in Table 3. The overall QoL of the participants was 69.56 ± 8.79 . Among the

Table 1. Demographic characteristics and profile of participants (N = 376).

Variables	Participants, n (%)
Sex	Male 141 (37.5)
	Female 235 (62.5)
Age (years), mean \pm SD	15-35 26.0 \pm 4.82
	15-19 39 (10.4)
	20-24 115 (30.6)
	25-29 121 (32.2)
	30-34 84 (22.3)
	≥ 35 17 (4.5)
Education	None 3 (0.8)
	Primary 15 (4.0)
	Secondary 145 (38.6)
	Tertiary 191 (50.8)
	Vocational 20 (5.3)
	Postgraduate 2 (0.5)
Marital status	Single 50 (13.3)
	Married 76 (20.2)
	Common-law spouse 241 (64.1)
	Separated 7 (1.9)
	Widowed 2 (0.5)
Employment/regular activity	Yes 167 (44.4)
	No 209 (55.6)
Financial source for expenses	Savings/salary 212 (56.4)
	Family 105 (27.9)
	Spouse 49 (13.0)
	Children 2 (0.5)
	Not specified 7 (1.9)
	None 1 (0.3)
Presence of illness	No 359 (95.5)
	Not diagnosed but feels like they have 17 (4.5)
Disease of the respondent's sibling	Cardiovascular 46 (12.2)
	Lung 8 (2.1)
	Kidney 13 (3.5)
	Endocrine 42 (11.2)
	Gastrointestinal 1 (0.3)
	CNS disorder 54 (14.4)
	Intellectual disability 83 (22.1)
	Learning disability 43 (11.4)
	Psychiatric disorder 20 (5.3)
	Cancer 38 (10.1)
	PWD 28 (7.4)

transformed mean scores, social relationships had the highest score, followed in decreasing order by psychological health, environment, and physical health. Scores for perceived QoL and perceived health state were 3.55 and 3.58, respectively. As shown on Table 4, all except three respondents had a fair to good quality of life.

Family function was shown to have a significant positive correlation with overall quality of life ($r_s = 0.27$, $p < 0.001$), the physical domain ($r_s = 0.11$, $p = 0.032$), psychological health domain ($r_s = 0.27$, $p < 0.001$), social relationships domain ($r_s = 0.25$, $p < 0.001$), and environment domain ($r_s = 0.24$, $p < 0.001$). The correlation coefficients ranged from 0.11 to 0.27, considered as weak positive correlation.¹⁶

Table 2. Family function classification, frequency distribution.

Family Function Classification ^a	Frequency n = 376 (%)	95% CI (%)
Highly dysfunctional	1 (0.27)	0.04, 1.88
Moderately dysfunctional	13 (3.46)	2.01, 5.88
Functionally at risk	46 (12.23)	9.28, 15.97
Moderately functional	113 (30.05)	25.61, 34.90
Highly functional	203 (53.99)	48.90, 58.99

^aRaw scores were classified as highly dysfunctional (0 - 6), moderately dysfunctional (7 - 12), functionally at risk (13 - 18), moderately functional (19 - 24), and highly functional (25 - 30) as proposed by Powazki & Walsh.¹⁴

The scatterplot demonstrated that as the FF of young adults increased, their QoL also increased (Figure 1).

Table 4. Quality of life classification, frequency distribution.

Quality of life classification ^c	Frequency n = 376, (%)	95% CI (%)
Poor	3 (0.80)	0.26, 2.46
Fair	250 (66.49)	61.54, 71.10
Good	123 (32.71)	28.14, 37.64

^cRaw scores were classified as poor (26 - 60), fair (61 - 95), and good (96 - 130) quality of life according to the categorization of Dajpratham, Tantiriramai, & Lukkanapichonchut.¹⁵

Table 3. Quality of life (QoL) mean scores, untransformed and transformed.

Dimensions of Quality of Life	Untransformed Scores Mean ± SD	Transformed Scores ^b Mean ± SD
Overall quality of life	3.48 ± 0.44	69.56 ± 8.79
Physical health	3.28 ± 0.47	65.52 ± 9.48
Psychological health	3.59 ± 0.51	71.90 ± 10.10
Social relationships	3.77 ± 0.66	75.48 ± 13.21
Environment	3.43 ± 0.62	68.66 ± 12.38
Perceived quality of life	3.55 ± 0.87	71.17 ± 17.43
Perceived health state	3.58 ± 0.78	71.60 ± 15.58

^bScores were transformed using the standard scoring mechanics for the WHOQoL-BREF raw scores by multiplying each domain by 20.¹²

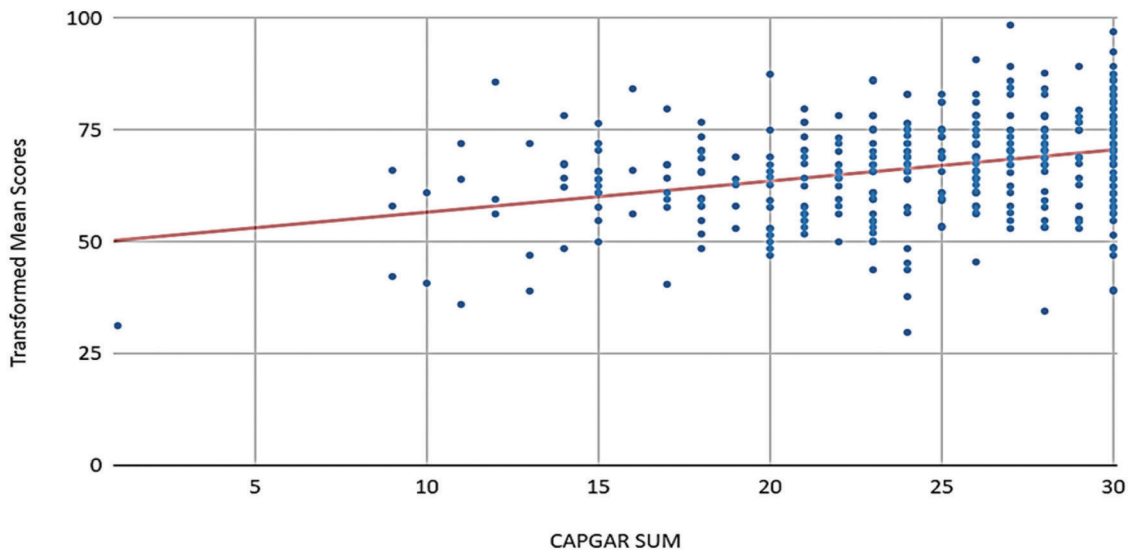


Figure 1. Scatter plot of CAPGAR (x-axis) and transformed domain total of WHOQOL-BREF Score (y-axis).

Discussion

Family function is an essential factor affecting the quality of life of an individual. The objective of this study was to determine the correlation of FF and the QoL among healthy young adults with siblings with chronic diseases.

Sharpe found that adults who have chronically-ill siblings appear to be more compassionate and resilient; he also indicated the possible negative effects on the psychological and emotional life of those individuals with a chronically-ill sibling.⁵ The present study shows that most young adults have fair QoL, where psychological and social indicators scored highest. This proportion of participants is consistent with the findings of Almeida-Brasil who explained that in this stage of life, a functional peak of networks of relationships are established, with much time devoted on friendship.¹⁷

The physical health domain, which includes activities of daily living, dependence on medicinal substances and medical aids, enough energy and mobility, pain and discomfort, sleep and rest, and work capacity, had the least correlation with family function ($r_s = 0.11$, $p = 0.032$). These factors play a vital role in a person's functionality, and could affect an individual's QoL. The low correlation of physical health can be attributed to the participants' age and medical status, being young adults with no comorbidities or illnesses. The respondents may tend to ignore their physical complaints, as there may be a sense of omnipotence when caring for others, as shown by Ribe.¹⁸ Hence, the physical domain is less likely to have strong correlation with family function.

Among the other components of the WHO-QoL-BREF, the psychological domain has the highest correlation ($r = 0.27$, $p < 0.001$) with FF. Rossiter and Sharpe concluded that having a brother or sister with disability has a negative effect on psychological functioning, caretaking, and peer activities but it has a positive effect on the quality of the sibling relationship.⁵ Other studies also show that family closeness, greater sensitivity and personal growth are some of the positive effects of having a sibling with disability. Moreover, Patterson mentions that coping which is directed at keeping the family integrated - by doing things together as a family - maintains a good outlook in life, thus corresponding to having a good family function.¹⁹ Filipino culture, deeply rooted in its family-centered attitude, is a potential factor to

consider in determining function, especially when it comes to care and support for loved ones. The use of CAPGAR questionnaire in this study looked into the functional state of the patient's family because chronic illness and disability represent a certain stress to the family, as in the study of Smilkstein.²⁰

Majority of the participants in this research have highly functional families. Panganiban cited that close family ties and close-knit communities influence FF.²¹ Friends and neighbors alike are ready to help the family in times of crisis. This observation is consistent with the findings of Love and Murdock, who observed that attachment (operationalized as paternal and maternal care) was a significant factor for the well-being of a young adult, and that membership in an intact, biological family is associated with higher levels of psychological well-being.²²

It is possible that siblings of persons with chronic illnesses may still have a positive outlook and good QoL because they accept and understand the need of their sibling. Menguito and Teng-Calleja discussed "*bahala na*" as a reflection of the Filipino's courage, optimism, and hope which serve as springboards towards success.²³ Though perhaps taken as a form of surrender on one hand, the expression "*bahala na*" implies confidence and motivation to keep facing whatever may come.

Questions 28 and 29 of the Filipino version of WHOQoL-BREF allow the participants to share their thoughts in improving their QoL through these questions: "*Anu-ano ang mga bagay na makakadagdag ng kalidad sa inyong buhay?*" and "*Paano sa inyong palagay, maitataas ang kalidad ng inyong buhay?*" Most participants said that QoL can be improved through education and opportunities to attain financial growth. This way, they can support their families better, making them happier with a sense of accomplishment. Aside from personal means to attain financial growth, the participants also count on the government's assistance in lowering prices of commodities, better support for persons with disability (PWDs), and even better public transportation to lighten traffic. These answers fall under the environment domain, which has the second lowest correlation to FF. Other answers include quality time and communication within families, which further highlights the importance Filipinos give towards their family function. Economy and socialization may remain at the core of what it means to be a family, as mentioned earlier. Roces calls this core "*politica de familia*" and claims that

Filipinos “perceive the world in terms of how outside resources could be used to improve the status of the family in socio-economic terms.”²⁴ Filipinos, in spite of inherent challenges, have a “primary allegiance” to the family - often viewing the self as an extension of it, and holding the family’s wellbeing to be more important than one’s own.²⁴

In summary, this study shows that among young adults with chronically-ill siblings, family function is high and correlates with quality of life. A limitation of this study is the study population came from certain barangays, hospitals, and institutions which approved the request for data collection. Several hospitals and non-government organizations declined the invitation to participate, citing the Data Privacy Act.

Future studies can be done using qualitative methods to explore the relationship between family function and quality of life in more depth. One-on-one interviews or focus group discussions may provide better understanding of the feelings, challenges and experiences of the chronically ill individual’s siblings which may complement the WHOQOL BREF and CAPGAR findings. Future studies can also have participants from a younger population starting from 14 years of age, as the teenage years are crucial in holistic development and any significant findings in this age group would thus need support from the family and society. Further studies may likewise perform separate analyses per category of disease to identify more precisely which diseases have the greatest impact on the quality of life and family function.

This study showed that despite having chronically-ill siblings, more than half of young adults had highly functional families. Two-thirds of the participants had fair quality of life. There is a weak but significant positive correlation between family function and quality of life among young adults with a sibling suffering from a chronic debilitating illness.

Acknowledgements

We wish to acknowledge and thank the barangay captains and PWD focal person representatives whose assistance greatly expedited our search for participants, the participants who patiently and candidly answered the questionnaires, and the UERMMMCI and World Citi Medical Center.

Source of funding

This research was funded by the UERMMMCI College of Medicine.

Conflict of interest

The authors declare no conflict of interest.

References

1. Secinti E, Thompson EJ, Richards M, Gaysina D. Research review: Childhood chronic physical illness and adult emotional health - a systematic review and meta-analysis. *J Child Psychol Psychiatr* 2017; 58(7): 753-69. doi: 10.1111/jcpp.12727. Epub 2017 Apr 27.
2. Ogunlana MO, Dada OO, Oyewo OS, Odole AC, Ogunsan MO. Quality of life and burden of informal caregivers of stroke survivors. *Hong Kong Physiother J* 2014; 32(1): 6-12.
3. Berggreen SM. A study of the mental health of the near relatives of twenty multihandicapped children. *Acta Paediatr* 1971; 60: 6-24.
4. Mattsson A. Long-term physical illness in childhood: A challenge to psychosocial adaptation. *Pediatrics* 1972; 50(5): 801-11.
5. Sharpe D, Rossiter L. Siblings of children with a chronic illness: A meta-analysis. *J Pediatr Psychol* 2002; 27(8): 699-710.
6. McKeever P. Siblings of chronically-ill children: A literature review with implications for research and practice. *Am J Orthopsychiatr* 1983; 53(2): 209.
7. Frawley JE, Hebert RS. Seriously ill pediatric patients who transition to adulthood. *J Palliat Med* 2018; 21(2): 257-8.
8. Rana P, Mishra D. Quality of life of unaffected siblings of children with chronic neurological disorders. *Indian J Pediatr* 2015; 82(6): 545-8. doi: 10.1007/s12098-014-1672-4. Epub 2015 Feb 3.
9. Department of Health. The 2015 Health Statistics. Available from: <https://www.doh.gov.ph/sites/default/files/publications/2015PHS.pdf>. Accessed May 2019.
10. Rodríguez-Sánchez E, Pérez-Peñaranda A, Losada-Baltar A, et al. Relationships between quality of life and family function in caregiver. *BMC Fam Pract* 2011; 12:19. doi: 10.1186/1471-2296-12-19
11. Medina M. Section of Supportive Hospice & Palliative Medicine. The Comprehensive Family APGAR (CAPGAR). In: *Compendium of Filipino Assessment Tools for Clinical Practice and Research*. Available from: <https://sites.google.com/site/hospiceandpalliativemedicine/compendium-of-filipino-assessment-tools>
12. World Health Organization. World Health Organization Quality of Life-BREF: Introduction, administration, scoring and generic version of the assessment, program on mental health. 1996. Available from: http://www.who.int/mental_health/media/en/76.pdf.

13. Good MD, Smilkstein G, Good BJ, Shaffer T, Arons T. The Family APGAR Index: A study on construct validity. *J Fam Pract* 1979; 8(3): 577-82.
14. Powazki RD, Walsh D. Family distress in palliative medicine: A pilot study of the family APGAR scale. *Am J Hosp Palliat Care*, 2002; 19(6).
15. Dajpratham P, Tantiriramai S, Lukkanapichonchut P. Health related quality of life among the Thai people with unilateral lower limb amputation. *J Assoc Med Thai = Chotmaihet thangphaet*, 2011; 94(2): 250-5. Available from: <https://www.ncbi.nlm.nih.gov/pubmed/21534374>. Accessed May 16, 2019.
16. Daniel WW, Cross CL. *Biostatistics: A foundation for analysis in the health sciences*. 11th ed. Wiley 2013; 191-3.
17. Almeida-Brasil CC, Silveira MR, Silva KR, et al. Quality of life and associated characteristics: Application of WHOQOL-BREF in the context of primary health care. *Revista Ciência & Saúde Coletiva* 2017; 22(5).
18. Ribé JM, Salamero M, Testor CP, et al. Quality of life in family caregivers of schizophrenia patients in Spain: Caregiver characteristics, caregiving burden, family functioning, and social and professional support. *Int J Psychiatry Clin Pract* 2018; 22(1): 25-33.
19. Patterson JM, McCubbin HI, Warwick WI. The impact of family functioning on health changes in children with cystic fibrosis. *Soc Sci Med* 1990; 31(2): 159-64.
20. Smilkstein G. The family APGAR: A proposal for a family function test and its use by physicians. *J Fam Pract* 1978; 6(6): 1231-9.
21. Panganiban-Corales AT, Medina MF. Family resources study: Part 1: Family resources, family function and caregiver strain in childhood cancer. *Asia Pac Fam Med* 2011; 10:14.
22. Love KM, Murdock TB. Attachment to parents and psychological well-being: An examination of young adult college students in intact families and stepfamilies. *J Fam Psychol* 2004; 18(4): 600-8. doi:10.1037/0893-3200.18.4.600.
23. Menguito MM, Teng-Calleja M. Bahala na as an expression of the Filipino's courage, hope, optimism, self-efficacy, and search for the sacred. *Phil J Psychol* 2010; 43(1): 1-26.
24. Roces M. Kinship politics in post-war Philippines: The Lopez Family, 1945-1989. *Mod Asian Stud*, 2000; 34(1): 181-221. Available from: <http://www.jstor.org/stable/313115>.
-