



Caregivers Burden as Risk Factor against Quality of Life of Caregivers of Cerebral Palsy Patients: Moderating Role of Social Support

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Authors' contributions

This work was carried out in collaboration between both authors. Author KDK designed the study, performed the statistical analysis, wrote the protocol and wrote the first draft of the manuscript. Author FN managed the analyses of the study and managed the literature searches. Both authors read and approved the final manuscript.

Article Information

DOI: 10.9734/IINDJ/2017/39050

Editor(s):

(1) Elena Cecilia Rosca, Department of Neurology, University of Medicine and Pharmacy, Romania.

Reviewers:

(1) Mary V. Seeman, University of Toronto, Canada.

(2) Roslyn Livingstone, Canada.

Complete Peer review History: <http://www.sciencedomain.org/review-history/23052>

Original Research Article

Received 10th November 2017
Accepted 26th January 2018
Published 6th February 2018

ABSTRACT

The consequences of living with a chronic condition such as Cerebral Palsy (CP) do not only affect the child but other members of the family. However, researchers have neglected the caregivers in their quest for the consequences of the disorder. The present study investigated the impact of caregiver's burden on quality of life (QoL) of caregivers. The role of social support in ameliorating the negative consequences of the caregiver's burden on QoL of the caregivers was also assessed. One hundred and thirty (130) caregivers in two government hospitals and two Non-governmental agencies were conveniently selected to complete the Caregivers Burden Inventory (CBS), the Multidimensional Scale of Perceived Support (MSPS) and the WHO Quality of Life-BREF (WHOQOL-BREF). Pearson correlation and regression analysis were the statistical tools used for data analysis. The findings revealed that caregiver burden has a significant negative correlation with QoL of caregivers. Social support moderated the relationship between caregiver's burden and QoL. The implication of the findings for nursing practice and informal caregiving are discussed.

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Keywords: Quality of life; caregiver's burden; social support; caregivers; cerebral palsy.

1. INTRODUCTION

One of the most frequent causes of chronic disability in children is cerebral palsy (CP) [1,2]. Globally, the prevalence of CP is 1.5 – 2.5 per 1000 live births [1]. Reports in Ghana indicate that about 4 to 5 children out of every 1000 births suffer from CP [3]. The special needs of such children add to the emotional, physical and financial strain inherent in raising them [4]. CP requires long-term management and as such, the presence of caregivers is immensely crucial to these children. However, studies [e.g., 2,3] on CP have focused on patients with CP neglecting the caregivers. In Ghana, CP has been associated with numerous myths and beliefs as a result of incorrect information regarding the etiology of the disorder [4]. The myths and beliefs about the causes of the disease also prevent others from providing the needed support to the patients and their caregivers. It is therefore essential to assess how social support enhances the impact of caregiver's burden on quality of life of caregivers in Ghana.

The term CP refers to a group of permanent disorders associated with the development of movement and posture which has been attributed to non-progressive disturbances that occur during the development of the foetal or infant brain [5]. Reported characteristics of CP include impaired motor function, sensory and intellectual impairment, as well as complex limitations in self-care functions [5]. In the absence of a cure for CP Patients arise the need to enhance the quality of life of a child. Activities such as trips to the hospital for routine visits, physiotherapy sessions and assisting with the child's daily routine aid to enhance the QoL of these children. The success of these activities may depend on the caregiver [1].

The enormous effects of living with a chronic condition such as CP affects both the child and especially the caregiver, who often spends much time with the CP patient [6]. It is therefore prudent to assess the consequences of the disorder on the caregiver. A caregiver concerning CP is one with the primary responsibility of encouraging a child to become independent in his or her daily activities [7]. According to [8], it is a requirement for caregivers to sacrifice facets of their well-being often so that they can have

enough time to care for the patient. Caregivers do compromise their physical health and psychological well-being because they continually have to juggle between the needs of their children and their own needs [9,10]. In fact, caregivers need ample time because children with CP require continuous special care, frequent medical check-ups, and physiotherapy management [11].

The provision of a high level of care required by a child can affect and impact the quality of life (QoL) of the caregiver. QoL is an individual's view of his/her place in life, in the context of the customs and value systems in which he/she lives, and also concerning his goals, potential, standards and concerns [12]. Taking care of a child is connected with different physical, psychological and social changes for the caregivers. One of the most affected physical, psychological and social changes is the social network of the caregiver which results in lower QoL. This is due to the lack of opportunities for leisure activities, impossibility to go out and associate with friends and changes in family routines [13].

The QoL of the caregiver of a CP patient may be dependent on certain conditions, experiences, and activities that threaten the effort of the caregivers in achieving their purpose [14]. These factors are called caregivers burden. Caregivers burden are the unique difficulties that caregivers encounter [15]. Many factors contribute to the burden of the caregivers. Among these factors include the characteristics of the patient, the responsibilities performed, time spent in caregiving and the characteristics of the caregivers themselves [11]. The commitment to long-term care and the significant amount of time devoted to the care of the child can negatively affect the QoL of the caregiver [16].

Researchers have indicated that perceived social support buffers the impact of the caregivers' burden on the quality of life of the caregivers [17,18]. Social support deals with having someone to count on in difficult situations to receive the material, emotional or effective help [17,19]. When caregivers do not have people to depend on for their material, emotional or sentimental help, it increases their level of psychological distress and thus affects their quality of life.

According to the Risk and Protective Factor Model [20], there are some factors which can either increase or decrease the well-being and quality of life of caregivers. The presence of protective factors boosts the well-being of individuals, and that of risk factor diminishes the well-being of individuals. The Risk and Protective Factor Model view caregiver's burden as a risk factor which lowers the QoL of caregivers [21, 22]. The Risk also predicts social support, and Protective Model as a protective factor that helps improves the QoL of caregivers. A study by [22] indicated that the burden associated with caregiving negatively predicted the quality of life of the caregivers.

There is evidence to support the fact that the level of caregiver's burden determines their QoL [23]. However, most of them focus on general caregiving with different disabilities. For example, a study conducted by [23] indicated that caregivers burden negatively affect the QoL of caregivers of epileptic children. Similarly, [12] revealed that increased caregiver burden was significantly related to lower health-related QoL among caregivers of stroke patients. Few studies have concentrated on caregivers. For example, [9] study revealed that child behaviour, caregiving demands or burden, and family function were the significant predictors of quality of life among caregivers. [24] study also revealed that increased in caregiver's burden leads to decrease in quality of life of CP caregivers.

Studies [25,26] have also shown that social support may serve as a coping resource in optimising the well-being and health outcomes of caregivers. The level of available support from family, friends and significant others has consistently been shown to be associated with fewer reports of stress, anxiety, depression and better quality of life of caregivers [6,24]. [27] revealed that higher support was associated with lower psychological distress among the caregivers.

Most existing studies thus far reviewed are western oriented where people are perceived to be individualistic. Ghanaians, on the other hand, are seen to be collective [28,29]. This difference in cultural orientation does not make it appropriate to generalise the findings from the western countries to Ghana. The lack of studies in Ghana failed to examine the factors that can improve the relationship between caregiver's burden and quality of life of the caregivers. It is based on this that the present study was

conducted in Ghana to assess the influence of caregiver's burden on quality of life of caregivers. The study also sought to evaluate whether social support moderates the relationship between caregivers burden and quality of life of children with CP. Accordingly, the study aimed to test the following predictions:

1. There will be a significant negative relationship between caregiver's burden and quality of life of caregivers.
2. Social support will moderate the relationship between the caregiver's burden and the QoL of caregivers.

2. METHODS

2.1 Design

This study employed a quantitative approach using a survey. A cross sectional survey was adopted which sought participants' views using structured questionnaires to assess the QoL of caregivers. The cross-sectional design was appropriate because data was collected at one point in time.

2.2 Population

All caregivers (parents, relatives, and other associates) of children with CP being managed at the neuro-developmental Clinics (NDC) in two government and two Non-governmental institutions within Greater Accra that support children with CP served as the population. These people were used as target population because they served the purpose of the study.

2.3 Participants

Respondents for the study were recruited through the purposive sampling technique. The purposive sampling was done by utilizing only caregiver of children who have been diagnosed with CP. All the 130 questionnaires distributed were returned and used for the study representing a response rate of 100%. The selection of 130 respondents was based on [30] proposed criteria for selecting sample size $n > 50+8M$ where n = sample size, M = number of independent variables. In this study, there were two independent variables (caregiver's burden and social support) in the study. Base on this, the sample size is estimated to be more than 66 ($n > 66$). The 130 sample size is large enough to cater for non-response rate and achieve higher external validity. Among the respondents,

majority of them (90.8%) were females and 77.7% were married. The mean age of the 130 respondents is 35.85 (SD = 8.14) years with a modal age of 35 years. Majority of the respondents (90.8%) were Christians. (See Table 1 for description of the demographic characteristics).

Table 1. Demographic characteristics of the respondents

Variable	Frequency	Percent
Sex		
• Female	118	90.8
• Male	12	9.2
Age		
Mean age	35.85 (SD=8.14) years	Modal age of 35 years
Marital status		
• Married	101	77.7
• Single	14	10.8
• Divorced	4	3.1
• Separated	7	5.4
• Others	4	3.1
Religion		
• Christianity	118	90.8
• Islam	12	9.2

2.4 Measures

Three scales were used in measuring the variables of interest. They included measures of caregiver’s burden, social support and quality of life among the caregivers. Measures were developed to assess demographic characteristics of the respondents including gender, age, religion and marital status. The scales used are described below.

2.4.1 Caregiver’s burden

Caregiver’s burden was measured using the Caregivers Burden Inventory [31]. The Caregivers Burden Inventory (CBI) measures the burden of caregivers of patients with different disorders. The CBI consists of 20-items assessed on a four point Likert scale with a range from never (0) to often (3). [31] found the Cronbach alpha for internal consistency of the scale to be .91. Scores ranged from 0–60 with a higher score indicating higher level of perceived caregiver’s burden.

2.4.2 Social support

Caregivers social support was measured using the Multidimensional Scale of Perceived Support

(MSPS) designed by [32]. The MSPS is a validated 12-item instrument designed to assess perceptions about support from family, friends and others. Participants responded to the items using a five point Likert scale that ranged from strongly agree to strongly disagree. [32] reported a Cronbach alpha of .79 for the scale. The social support scale was scored on a five point Likert scale that ranged from 0 – 4. Scores ranged from 0 – 48 with higher scores indicating higher levels of perceived parental support.

2.4.3 Quality of life

Quality of life was measured using the WHO Quality of Life-BREF [12]. The WHOQOL assesses the individual’s perceptions in the context of their culture and value systems, and their personal goals, standards and concerns. The WHOQOL-BREF consists of 26 items which measure four broad domains including the physical health, psychological health, social relationships, and environment. The scale is measured on a five point Likert scale ranging from strongly disagree (1) to strongly agree (5). [33] found internal consistency of the scale to range from .76 – .90 across domains. Scores ranging from 26 - 130 were awarded with a higher score indicating higher QoL.

2.5 Procedure

Ethical approval was sought from the Noguchi Memorial Institute for Medical Research and clearance from the Ghana Health Service Regional Health Directorate (Greater Accra) before the commencement of the research. Institutional approval was sought before data collection. Questionnaires were then sent to the facilities and administered face-to-face to caregivers who were present and willing to participate in the study. Consent forms were signed by participants who expressed the willingness to partake in the study. The caregivers completed the questionnaires themselves. In some cases, the questionnaires were read to the caregivers by some research assistants who were trained to help in data collection.

3. DATA ANALYSIS

Statistical Package for Social Sciences (SPSS), version 20.0 was used for statistical analysis. Two hypotheses were tested. Hypothesis 1 was analyzed using the Pearson r because the relationship between the components of

caregiver's burden and quality of life was established (see Table 2). Hierarchical multiple regression analysis was used to determine the moderating role of social support on the relationship between caregiver's burden and QoL as proposed in hypothesis 2 (see Table 3).

4. RESULTS

The results obtained from the analysis of data collected from the 130 caregivers are summarized in the Tables below.

Table 2. Relationship between caregivers burden and quality of life

Variables	Quality of life of caregivers	
	r	P
Physical Burden	-.398	.001**
Emotional Burden	-.308	.001**
Family Burden	-.477	.001**
Individual Burden	-.447	.001**
Financial Burden	-.486	.001**
Total Caregivers Burden	-.504	.001**

** $p < 0.01$

Table 2 shows that all the component of caregiver's burden was negatively correlated with QoL. QoL had a significantly negative relationship with physical burden ($r = -.398, p < .05$), emotional burden ($r = -.308, p < .05$), family burden ($r = -.477, p < .05$), individual burden ($r = -.447, p < .05$) and financial burden ($r = -.486, p < .05$). Overall, caregivers' burden was found to correlate negatively and significantly with QoL of caregivers ($r = -.504, p < .05$). This supported the first hypothesis which stated that "there will be a significant negative relationship between primary stressors and QoL of caregivers".

The regression results (Table 3, Model 1) indicated that caregivers' burden explained a significant 25.4% variance in caregivers' quality of life. When the moderator (social support) was fed into the model in the second step, the two variables (social support and caregivers burden) jointly explained a significant variance in caregivers' quality of life ($R^2 = .330, F_{(2, 127)} = 31.275, p = .000$) with social support adding 7.6% of the variance in caregivers' quality of life. In the third step of the regression analysis indicating whether moderation effect exists, the interaction term between caregivers' burden (predictor) and social support (moderator) was fed into the model. The results indicated that the interaction term between caregivers' burden (predictor) and social support (moderator) explained a significant increase in variance in quality of life ($R^2 = .446, F_{(3, 126)} = 22.192, p = .000$). Thus, social support is a significant moderator of the relationship between caregiver's burden and quality of life which supports the second hypothesis.

5. DISCUSSION

The study was first aimed at assessing the influence of caregiver's burden on quality of life of caregivers. The results of the study indicated that caregivers burden have a significant negative correlation with QoL among caregivers. This means that an increase in the burden of caregivers is associated with a decrease in their QoL. This finding is congruent with previous findings revealed by [24] which found that higher caregiver's burden was associated with lower quality of life among caregivers. Similarly, the negative relationship between caregiver's burden and QoL agrees with the study by [23]. According to [18], caregiver burden can culminate in acute and chronic physical disorders, resulting in

Table 3. Results of hierarchical multiple regression analyses for the moderation effect of social support on the relationship between caregivers burden and quality of life

		B	SEB	β	T	P
Model 1	(Constant)	92.375	3.416		27.043	
	Caregivers Burden	-.514	.078	-.504	-6.609	.000
Model 1 summary: $R^2 = .254, F_{(1, 128)} = 43.672, p = .000$						
Model 2	(Constant)	78.378	4.923		15.919	
	Caregivers Burden	-.362	.084	-.355	-4.298	.000
	Social Support	.383	.101	.313	3.785	.000
Model 2 summary: $R^2 = .330, F_{(2, 127)} = 31.275, p = .000$						
Model 3	(Constant)	91.480	8.975		10.193	.000
	Caregivers Burden CB)	-.647	.184	-.634	-3.521	.001
	Social Support (SS)	-.161	.328	-.132	-.492	.624
	Interaction (CB X SS)	.938	.539	.416	1.740	.024
Model 3 summary: $R^2 = .446, F_{(3, 126)} = 22.192, p = .000$						

isolation and depression, as well as financial disequilibrium, reduction in libido and self-accusation which all affect the quality of life of the caregiver. Also, caregivers' burden imposes a high level of stress among the caregivers. A heightened level of stress due to the caregiver's burden affects the psychological functioning and well-being of the person and thus leads to lower quality of life.

The study also predicted that social support will moderate the relationship between caregiver's burden and quality of life. The findings indicated a moderating effect of social support on the relationship between caregiver's burden and quality of life with social support accounting for 44.6% of the variance in QoL. This means that a caregiver with higher caregiving burden when exposed to social support will exhibit a better quality of life compared to a caregiver without social support. Thus, social support contributes to alleviating the negative consequences of stress and burden of the caregiver in caring for a child. This finding supports the results from the study conducted by [18] which indicated that social support play a partial role as a moderator in the relationship between burden and quality of life. Social support for caregivers is important to prevent health complications such as bio-psycho-social stress, and provides favourable conditions for quality of life, by allowing greater freedom to develop in daily activities. Based on this, the negative consequences associated with higher burden may not be felt much when the level of social support enjoyed by the caregiver is qualitatively and quantitatively higher. Social support received from friends, family members and other members of the society in the form of money, encouragement, counselling etc. can serve as catalyst for boosting the wellbeing of the caregivers. As explained by [17], the extent to which the burden associated with caregiving can affect the well-being of an individual will depend on the quality of support they receive from the family and significant others. Invariably, social support serves as a coping tool in optimizing the well-being and health outcomes of caregivers.

Though the present study took all possible steps to provide the findings in a holistic way, the study had some limitations. The findings of this study should be interpreted in light of its limitations.

This study relied on self-report measures which are subject to social desirable effects. Due to the perceptual nature of the data, there is the possibility of a perceptual bias. Nevertheless, the

researcher made sure the respondents remained anonymous which reduced the socially desirable responses but could not control for the perceptual bias.

Also, this empirical study confines itself to a correlational survey method, which leaves room for speculation with regard to causality among the variables. The researcher used purposive sampling technique instead of random sampling. By that, not all the caregivers of children with cerebral palsy had equal chance of participating in the study. The purposive sampling however became appropriate because there was no updated and current sample frame from which respondents could be randomly selected. Using longitudinal approach will help in inferring causality.

In spite of the limitations, there are a number of implications that can be inferred from the study. The findings of this study have implications for nursing practice, informal caregiving and policy formulation.

For nursing practice, findings of this study showed that burden associated with caring for CP patients negatively affect the QoL of caregivers. It also shows that adequate social support can ameliorate the negative consequences of burden on QoL of caregivers. There is the need for nurses to be enlightened on the enormous burden that caregivers encounter and its consequences on reducing the QoL of caregivers in order for them to provide the caregivers with the needed support.

Caregivers need the knowledge and skills pertinent to the care they are providing for the children with cerebral palsy. Informal caregivers need to educate themselves about the disability (cerebral palsy), managing stress, coping with depression and anxiety and developing proper caregiving techniques. There is also the need for informal caregivers to seek financial, social and psychological support to ease the burden, stress, depression and anxiety they encounter. Health institutions and other facilities that deal with disabilities in Ghana can develop educational programmes in which children with cerebral palsy and their families, especially caregivers can participate in order to learn new independent living and coping skills.

6. CONCLUSION

Over the years, researchers and practitioners have been emphasising on the well-being and

health of the children with disabilities. The health of the caregiver, however, is both a cause and a consequence of the health of the child. The study in its entirety has revealed that caregivers burden contribute negatively to the QoL of caregivers. Social support moderated the relationship between caregiver's burden and QoL of the caregivers. Therefore, there is the need to provide adequate support to caregivers to boost their quality of life. There is also the need for mass education on the causes of CP as means of controlling the myths and legends about the origins of CP.

CONSENT

As per international standard or university standard, patient's written consent has been collected and preserved by the authors.

ETHICAL APPROVAL

As per international standard or university standard, written approval of Ethics committee has been collected and preserved by the authors.

COMPETING INTERESTS

Authors have declared that no competing interests exist.

REFERENCES

1. Blair E. Epidemiology of the cerebral palsies. *Orthopedic Clinics of North America*. 2010;41(4):441-455.
2. Snider L, Majnemer A, Darsaklis V. Virtual reality as a therapeutic modality for children with cerebral palsy. *Developmental Neuro Rehabilitation*. 2010; 13(2):120-128.
3. Tessier DW, Hefner JL, Newmeyer A. Factors related to psychosocial quality of life for children with cerebral palsy. *International Journal of Pediatrics*. 2014; 14:1-6.
4. Austin JK, Dunn DW, Johnson CS, Perkins SM. Behavioral issues involving children and adolescents with epilepsy and the impact of their families. *Epilepsy & Behavior*. 2004;5:33-41.
5. Rosenbaum PNP, Leviton A, Goldstein M, Bax M, Damiano D, Dan B, Jacobsson B. A report: The definition and classification of cerebral palsy. *Developmental Medicine & Child Neurology*. 2007;49:8-14.
6. Bruns A, Moe H, Jennings F, Ca S, Natour J. Quality of life and impact of the disease on primary caregivers of juvenile idiopathic arthritis patients. *Joint Bone Spine*. 2008; 75:149-154.
7. Mancini MC, Coster WJ, Trombly CA, Heeren TC. Predicting elementary school participation in children with disabilities. *Arch Phys Med Rehabil*. 2002;81:339-347.
8. Eker L, Tuzun E. An evaluation of quality of life of mothers of children with cerebral palsy. *Disability and Rehabilitation*. 2004; 26:1354-1359.
9. Raina P, O'Donnell M, Rosenbaum P, Brehaut J, Walter SD, Russell D, Swinton M, Zhu B, Wood E. The health and well-being of caregivers of children with cerebral palsy. *Pediatrics*. 2005;115(6): 626-636.
10. Parkes R, Caravale D, Marcelli P, Franco B, Colver C. Parenting stress and children with cerebral palsy: A European cross-sectional survey. *Developmental Medicine & Child Neurology*. 2011;8:815-821.
11. Erdoganoglu Y, Gunel MK. Investigation of health-related quality of life of families with have children with cerebral palsy. *Bulletin of Community Medicine*. 2007;26(2):35-39.
12. WHOQOL Group. The World Health Organization Quality of Life assessment: Position paper from the World Health Organization. *Soc Sci Med*. 1991;41: 1403-1409.
13. Amendola F, Oliveira MAC, Alvarenga MRM. Influence of social support on the quality of life of family caregivers while caring for people with dependence. *Rev Esc Enferm USP*. 2011;45(4):880-5.
14. Dezot AN, Alexandre AMC, Freire MHS, Mercês NNA, Mazza VA. Social support to the families of children with CP. *Acta Paul Enferm*. 2014;28(2):172-6.
15. Segui JD, Ortiz-Talo M, de Diego Y. Factores asociados al estrés del cuidador primario de niños con autismo: sobrecarga, psicopatología y estado de salud. *Anales de Psicología*. 2008;24(1): 100-105.
16. Klassen AF, Klassen R, Dix D, Pritchard S, Yanofsky R, O'donnell M, Scott A, Sung L. Impact of caring for a child with cancer on parents health-related quality of life. *J Clin Oncol*. 2008;26(36):5884-5889.
17. Burnette D, Duci V, Dhembo E. Psychological distress, social support, and quality of life among cancer caregivers in Albania. *Psychooncology*. 2016;12:16-21.

18. Oh H, Lee EO. Caregiver Burden and Social Support among Mothers Raising Children with Developmental Disabilities in South Korea. *International Journal of Disability, Development and Education*. 2009;56(2):149-167.
19. Sit JW, Wong TK, Clinton M, Li LS, Fong YM. Stroke care in the home: The impact of social support on the general health of family caregivers. *J Clin Nurs*. 2004;13: 816-24.
20. Marsh HW. The structure of academic self-concept: The Marsh/Shavelson model. *Journal of Educational Psychology*. 1990; 82(4):623-636.
21. Spooner C, Hall W, Lynskey M. Structural determinants of youth drug use, Australian National Council on Drugs, Woden, ACT; 2001.
22. Deniz RN, Inci F. The burden of care and quality of life of caregivers of Leukemia and Lymphoma Patients Following Peripheric stem cell transplantation. *Journal of Psychosocial Oncology*. 2015; 33(3):250-262
23. Westphal-Guitti AC, Alonso NB, Migliorini RC, da Silva TI, Azevedo AM, Caboclo LO, Sakamoto AC, Yacubian EM. Quality of life and burden in caregivers of patients with epilepsy. *J Neurosci Nurs*. 2007;39(6): 354-60.
24. Kato N, Jaarsma T, Okada I, Kagami Y, Endo M, Ono M, Kinugawa K. Quality of life and burden in caregivers at 3 months after left ventricular assist device implantation. *Supplement*. 2015;34(4):22–23.
25. King G, King S, Rosenbaum P, Goffin R. Family-centered caregiving and well-being of parents of children with disabilities: Linking process with outcome. *Journal of Pediatric Psychology*. 1999;24:41–53.
26. Zuurmond MA, Mahmud I, Polack S, Evans J. Understanding the Lives of Caregivers of Children with Cerebral Palsy in rural Bangladesh: Use of Mixed Methods. *Disability, CBR and Inclusive Development (DCID)*. 2015;26(2):136–142.
27. Frey KS, Greenberg MT, Fewell RR. Stress and coping among parents of handicapped children. *American Journal of Mental Retardation*. 2009;94:240–249.
28. Gotze H, Brahler E, Gansera L, Polzek N, Kohler N. Psychological distress and quality of life of palliative cancer patients and their caring relatives during home care. *Epub*. 2014;22(10):2775-82.
29. Hooley PJ, Butler G, Howlett JG. Quality of life, depression, and caregiver burden in outpatients with congestive heart failure. *Congest Heart Fail*. 2005;11(6):303-10.
30. Tabachnick BG, Fidell LS. *Multivariate analysis (3rd edition)*. HarperCollins College Publishers (New York, NY); 1996.
31. Lee SH, Wu SC. Determinants of burden and depression among family caregivers. *The Journal of Nursing Research*. 1998; 6(1):57-68.
32. Zimet GD, Dahlem NW, Zimet SG, Farley GK. The multidimensional scale of perceived social support. *Journal of Personality Assessment*. 1988;52:30-41.
33. Gulbrandsen N, Hjermsstad MJ, Wisløff F. Interpretation of quality of life scores in multiple myeloma by comparison with a reference population and assessment of the clinical importance of score differences. *Eur J Haematol*. 2004;72(3): 172-80.

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