

Influence of Sex Difference on Burden of Caregiving, Social Support and Quality of Life of Informal Caregivers of Patients with Cerebral Palsy

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Abstract

Study aim: The study investigated the influence of sex-difference on burden of caregiving, social support and quality of life of informal caregivers of patients with CP. **Material and methods:** The study adopted a cross-sectional survey research design. A total of 78 informal caregivers participated in this study. The quality of life was assessed using the World Health Organization Quality of Life Bref (WHOQOL-Bref). Also, social support was assessed using Multidimensional Scale of Perceived Social Support (MSPSS). However, the level of burden of caring for CP patients on caregivers was estimated with the use of Caregivers Strain Index (CSI). Mann Whitney U-test was used to test for the influence of sex difference on the caregivers' level of burden, social support and quality of life. The statistical significance was accepted for a p value of <0.05. **Results:** The outcome of this study showed that sex of the caregivers had substantial influence on the level of burden of caregiving and, physical, psychological, social and environmental domains of their quality of life. However, sex-difference of caregivers has no significance on their level of perceived social support. **Conclusion:** It was therefore concluded that sex-difference of informal caregivers of CP predicts the level of burden of caregiving and all domains of quality of life but cannot determine the level of perceived social support. It was thus recommended that World Health Organization Quality of Life Bref (WHOQOL-Bref), Caregivers Strain Index (CSI) and Multidimensional Scale of Perceived Social Support (MSPSS) measures should be introduced into clinical practice. Also, the clinicians/clinical staff should be trained in using and interpreting the measures.

Keywords

Gender, Caregiving, Social Support, Quality of Life and Cerebral Palsy

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1. Introduction

Despite the increase in the need of caregivers and the importance of providing care, there is little empirical research examine how men and women approach and cope with providing care for individuals with neurological disorders. The paucity of male caregivers in previous study samples was

remarkable however, one study that did include a comparable number of male and female caregivers found that the health of mothers and fathers of children with Down's syndrome suffered to a similar degree despite the mothers spending more time caring than fathers [24]. Therefore, there may be need to consider the health of male caregivers of children with cerebral palsy (CP) alongside females. However in turn, mothers, more than fathers, are susceptible to strain, stress and depression

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[13]. CP is the commonest physical disability in childhood globally [5]. CP is an umbrella term of conditions with great challenges, with serious impact on survivor's quality of life. This is so because it can affect virtually all human functions with a sudden onset that leaves the individual and the family members, ill prepared to deal with the impairments. CP has been considered as a chronic neurological disorder predominantly of the motor function, which occurs in children as a result of non-progressive insult to the immature brain [4].

Moreover, an informal caregiver is anyone who provides care and support at home, community or in care facilities to an adult friend or family member who is living with disability, chronically ill, elderly or palliative [22]. Caregivers' burden is defined as a strain or load borne by a person who cares for family member with disability [7]. Caregivers have often been defined as the second victims of the disease, to underline the level of their involvement in the care of patients and in particular, the level of stress they are under. It should be appreciated that they often take on this role under sudden and extreme circumstances, with minimal preparation and little guidance and support from healthcare systems [2]. Undoubtedly, care giving is a normal part of being a parent of any child. However, one can easily appreciate how providing the high level of care needed by a child with long term functional limitations, such as with CP could potentially become exhausting and thereby impact upon the physical and mental health of the caregiver [23]. The danger is that if the caregiver burden becomes too great and their health is compromised as a result, they may no longer be able to provide the vital care needed by the child, a notion which is very disconcerting [25]. A significant study in the past found that for parents who have children with an intellectual disability or developmental problems, mothers have lower levels of marital satisfaction, self-esteem, self-control and life goals, and more symptoms of stress and need for social support than fathers [17]. Also, [22] submitted that the sex difference of the caregivers of CP had an influence on their level of quality of life. Mothers and women in general tend to assume the responsibility of caring for children with CP, forgoing other occupational roles [18]. In addition, [6] found that over the year's parents of children with CP, compared with parents of healthy children, more frequently complain of experiencing severe and chronic stress, emotional and cognitive problems, as well as report numerous somatic complaints. In terms of demographic characteristics, the lower the socio-economic status of the family, the higher the level of strain experienced by the caregiver [9].

Furthermore, social support refers to an individual's subjective perception of support. When an individual feels that relatives, close friends and significant others recognize one's efforts in the areas of love, caring, behavior, values,

and give their support, the individual actually benefits from the practical support received. Some scholars also believe that social support is a source of value that comes from the substantial or unsubstantial assistance of friends and family [16]. The source of social support can be formal and informal. Formal sources of social support include healthcare professionals, social workers, teachers, social organizations, support groups and other professional organizations while informal sources of social support include spouse, friends, relatives, neighbors and colleagues. Also, the parents of disabled children receive more support from informal sources [14]. It has been stated that within the area of family and friends, the support of the spouse within the family is the most important support [23]. Studies have shown that social support could alleviate depression, increase sense of self-esteem, increase coping strategies and elevate life satisfaction and psychological well-being of an individual [11, 12, 15]. Likewise, measuring of the quality of life of caregivers caring for children with chronic disease provides an insight on the challenges faced by these caregivers while caring for the children [10]. Quality of life is usually described as an overall assessment of well-being across various broad domains. Equally, [19] outlines five domains of quality of life: physical status and functional abilities, psychological status and well-being, social interactions, economic and vocational status, religious status. The difficult and constant struggle to improve the child's health and development is accompanied by doubt, guilt and shame, which contributes to the deterioration of the quality of life of parents and informal caregivers [10]. Experiencing severe anxiety (e.g. before making a crucial decision) often times leads to feelings of helplessness and lack of control, and this in turn may contribute to feelings of parental incompetence [20]. Fatigue and frequent loneliness lower resistance to stress and disturb the normal regulation of emotions [7]. The study therefore investigated the influence of sex-difference on burden of caregiving, social support and quality of life of informal caregivers of patients with CP.

Research hypotheses

The following hypotheses were formulated and tested at the 0.05 alpha level.

1. Sex-difference of the informal caregiver would not significantly influence physical domain level of their quality of life.
2. Sex-difference of the informal caregiver would not significantly influence social domain level of quality of life of informal caregivers of patients with cerebral palsy.
3. Sex-difference of the informal caregivers would not significantly influence psychological domain of the level of quality of life of informal caregivers of patients with

cerebral palsy.

4. Sex-difference of the informal caregivers would not significantly influence environment domain of the level of quality of life of informal caregivers of patients with cerebral palsy.
5. Sex-difference of the informal caregivers would not significantly influence the burden of informal caregivers of patients with cerebral palsy.
6. Sex-difference of the informal caregivers would not significantly influence the perceived social support of informal caregivers of patients with cerebral palsy.

2. Methods

Research design

This was a correlational survey study of the influence of sex-difference on burden of caregiving, social support and quality of life of informal caregivers of patients with CP.

Population

The population for the study comprised all informal caregivers of patients with CP at:

1. Nnamdi Azikiwe University Teaching Hospital, Nnewi, Anambra state.
2. Chukwuemeka Odumegwu university teaching hospital, AmakuAwka, Anambra State.
3. University of Nigeria Teaching Hospital, Ituku Ozalla, Enugu State.
4. Enugu State Teaching Hospital, Park lane, Enugu State,
5. Federal Medical Center, Owerri, Imo State.
6. Federal Teaching Hospital, Abakiliki, Ebonyi State,
7. Federal Medical Center, Umuahia.

Sample size and sampling technique

A total of 78 informal caregivers participated in this study. They were recruited using the consecutive sampling technique. However, caregivers who stayed with the CP patient for less than 1 month before the day of data collection and caregivers who could not read and understand English language were excluded from the study.

Procedure for Data Collection

The study received ethical approval from the Research Ethics Committee in the above mentioned health institutions (NAUTH/CS/66/VOL.9/36) for permission to conduct this study and the subjects were then recruited consecutively. The study protocol was explained to all of the respondents and each of the recruited sought their consent. A total of 4

questionnaires were filled, a Bio-data form, World Health Organization Quality of Life-Bref (WHOQOL-Bref) questionnaire, Multidimensional Scale of Perceived Social Support (MSPSS) and Caregiver Strain Index (CSI) questionnaires were used to collect data on the respondent's socio-demographic and clinical profile, the quality of life, the social support and the level of burden respectively. The questionnaires were administered face to face by the researcher and the rate of retrieval was 100%.

Quality of life was assessed using the World Health Organization Quality of Life Bref (WHOQOL-Bref). This is a short form of the WHOQOL-100. It contains 26 items that covers 4 domains- physical health (7 items, Cronbach's $\alpha=0.703$) and psychological health (6 items Cronbach's $\alpha=0.762$), social relationship (3 items Cronbach $\alpha=0.703$) and environment (8 items, Cronbach's $\alpha=0.785$) and two others concerning overall quality of life and health. These two items are not included in the calculation of the domain score. The response scales are 5 point Likert type ranging from 1 (not at all/never/very/dissatisfied/very poor) to 5 (extremely/always/very satisfied/very good) and time frame, i.e. the previous two weeks. Higher scores indicate a better subjective quality of life. However, items 3 and 4 in domain 1 and item 26 in domain two are negatively phrased and therefore have to be reversely scored when computing these domain scores. The mean scores of item of each item is used to calculate the domain score. Domain scores were calculated by multiplying the mean of all item scores included in each domain by a factor of 4, and accordingly, potential scores of each domain range from 4-20. Where an item is missing the mean of other items in the domain is substituted.

Social support was assessed using Multidimensional Scale of Perceived Social Support (MSPSS). This consists 12 items and it was developed by [28]. It was designed to assess the perception of social support adequacy from the sources of family, friend and significant other. Here, participation is required to rate perception on 7 point likert-type scale ranging from strongly disagree (1) to very strongly (7). The score of MSPSS is the total of the individual item scores. It ranges from 7 to 84. Higher scores reflect higher perceived social support (46-68) while lower scores indicate low perceived social support (12-48).

The level of burden of caring for CP patients on caregivers was estimated with the use of Caregivers Strain Index (CSI). The CSI is 13 question tools that measures strain related to care provision. There is at least 1 item for each of the following major domains: employment financial, physical, social and time. Positive response on seven or more items on the index indicate a greater level of strain.

Validity and reliability of the instruments

Sullivan (2002) reported that the caregivers strain index construct validity is supported by correlations with the physical and emotional health and with subjective views of the care giving situation. CSI has a high internal consistency ($\alpha=0.86$).

Reliability and validity [27] are reported to be good and its sensitivity to change was found to be high in the study of physically challenged children and students.

MSPSS has been found to have good internal reliability with Cronbach's alpha (0.899), parallel form reliability (0.91) and test re-test reliability (0.764) in Pakistani young adults (Rizwan & Aftab, 2009). It also shows good internal consistency.

Procedure for Data Analysis

Descriptive statistics of frequency counts, percentage, range, mean and standard deviation was used to summarize the descriptive data. Mann Whitney U-test was used to test for the influence of sex difference on the caregivers' level of burden, social support and quality of life. Statistical significance was accepted for a p value of <0.05 . All the analyses were performed using the Statistical Package for the Social Sciences (SPSS) version 22.0.

3. Results

The results are presented in Tables 1 - 3.

A total of 78 caregivers (22 males and 56 females) caring for 78 patients (38 males and 39 females) with CP with mean ages of 36.54 ± 6.027 and 17.24 ± 16.06 respectively, participated in this study. Most of the caregivers were the mothers (65.4%) of the patients, while some of the caregivers were the fathers (28.2%) of the patient, the rest were informally employed (3.8%) and grandparents of the patient (2.6%). Majority of the caregivers (97.4%) lived with the patient while few (2.6%) did not live with the patient. Some of the patients with CP had co-morbidities (seizure-11.5%, visual impairment-1.3%, speech impairment-3.8% intellectual disability-1.3% speech and intellectual disorder-2.6%). Some patients had two caregivers (78.2%) while others had one caregiver (21.8%). The caregivers were all literates. High proportions of the informal caregivers were housewives (28.2%), while the least proportion were teachers and students (1.3% each) respectively. See Table 1.

The duration of care-giving of the patients with CP had a mean value of 15.39 ± 9.54 . The mean level of burden (8.35 ± 3.75) experienced by informal caregivers fell within the area depicting significant burden, while the mean total level of perceived social support (60.4 ± 10.97) showed that

they have a moderate level of social support. The total quality of life of the informal caregivers was relatively high in all domains (Total quality of life 3.91 ± 0.70 , Physical domain- 54.78 ± 14.92 , psychological domain- 59.36 ± 12.50 , social domain- 71.76 ± 17.26 , Environment- 63.36 ± 14.81). See Table 2.

Table 1. Socio-demographic Profiles of Participants.

Variable	Category	Frequency	Percent
Sex difference of patient.	Male	38	48.7
	Female	39	50.0
Number of caregivers	1.00	18	23.1
	2.00	56	71.8
	3.00	4	5.1
Relationship With Patient	Mother	51	65.4
	Father	22	28.2
	Employed	3	3.8
	Grand parents	2	2.6
Resident	Live with patient	76	97.4
	Do not live with patient.	2	2.6
Education level of patient	Informal	76	97.4
	Formal	2	2.6
Co-morbidity of patient	None	62	79.5
	visual impairment	1	1.3
	Speech impairment	3	3.8
	Intellectual impairment	1	1.3
	Speech and intellectual impairment	2	2.6
	Seizure	9	11.5
Sex difference of caregivers	Female	56	71.8
	Male	22	28.2
Number of caregivers	Sole	17	21.8
	Shared	61	78.2
Level of education of caregivers	Ssce	28	35.9
	Hnd	28	35.9
	Bsc	21	26.9
	Msc	1	1.3
Occupation of caregivers	Chef	4	5.1
	Housewife	22	28.2
	Trader	14	17.9
	Engr.	11	14.1
	Tailor	4	5.1
	Civil servant	21	26.9
	Student	1	1.3
	Teacher	1	1.3

Table 2. Comparison of Participant's Age and Duration of Caregiving.

Variable	N=78	Mean	Std. Deviation
Age of patient		17.24	± 16.06
Age of caregiver		36.54	± 6.03
Duration of caregiving		15.40	± 9.54
Total caregivers strain index		8.36	± 3.75
Physical health domain		54.78	± 14.92
Psychological health domain		59.36	± 12.50
Social relationships domains		71.76	± 17.26
Environment domain		63.36	± 14.81
Total quality of life		3.910	± 0.71

Variable	N=78	Mean	Std. Deviation
Significant others		5.37	±1.15
Family		5.39	±1.10
Friends		4.33	±1.38
Total social support		60.40	±10.97

The influence of sex-difference of the caregivers of CP on their level of burden, social support and quality of life

The caregiver’s burden was significantly influenced by their sex difference (p=0.007, u=374.5). There were more female caregivers than male. The sex difference of the caregivers also influenced their quality of life in all domain (physical domain p=0.001, u=260.0, psychological domain p= 0.001 u=314.0, social domain p= 0.001 u= 243.5, environment domain p=0.40, u=443.5) except the total level of perceived social support (p=0.13, u=452.0). See table 3.

Table 3. Mann- Whitney U-test showing the influence of sex-difference of the caregivers on their burden, level of social support and quality of life.

	Sex difference	Mean rank	
Caregivers strain index total	Female	43.81	U=374.50
	Male	28.52	p=0.007*
Significant others	Female	40.74	U=546.50
	Male	36.34	p=0.437
Family	Female	42.74	U=434.50
	Male	31.25	p=0.043*
Friends	Female	41.18	U=522.0
	Male	35.23	p=0.295
Total social support	Female	41.89	U=482.00
	Male	33.41	p=0.136
Physical health domain	Female	33.14	U=260.00
	Male	55.68	p=0.001*
Psychological domain	Female	34.12	U=314.50
	Male	53.20	p=0.001*
Social relationships domains	Female	32.85	U=243.50
	Male	56.43	p=0.001*
Environment domain	Female	36.24	U=433.50
	Male	47.80	p=0.040*
Total quality of life	Female	33.8	U=298.50
	Male	53.9	p=0.001*

Hypothesis testing

Hypothesis 1

Sex-difference of the informal caregiver will not significantly influence physical domain level of their quality of life.

Test statistics-Mann Whitney U-test

U-value=260.01

P-value =0.001

α -value=0.05

Judgment-since P-value is less than α -value, the hypothesis is hereby rejected.

Hypothesis 2

Sex-difference of the informal caregiver will not significantly

influence psychological domain level of quality of life of informal caregivers of patients with cerebral palsy.

Test statistics-Mann Whitney U-test

U-value=314.50

P-value =0.001

α -value =0.05

Judgment-since P-value is less than α -value, the hypothesis is hereby rejected.

Hypothesis 3

Sex-difference of the informal caregivers will not significantly influence social domain of the level of quality of life of informal caregivers of patients with cerebral palsy.

Test statistics—Mann Whitney U-test

U-value=243.50

P-value =0.001

α -value =0.05

Judgment-since P-value is less than α -value, the hypothesis is hereby rejected.

Hypothesis 4

Sex-difference of the informal caregivers will not significantly influence environment domain of the level of quality of life of informal caregivers of patients with cerebral palsy.

Test statistics—Mann Whitney U-test

U-value = 433.50

P-value=0.040

α -value=0.05

Judgment-since P-value is less than α -value, the hypothesis is hereby rejected.

Hypothesis 5

Sex-difference of the informal caregivers will not significantly influence the burden of informal caregivers of patients with cerebral palsy.

Test statistics—Mann Whitney U-test

U-value=374.50

P-value=0.007

α -value =0.05

Judgment-since P-value is less than α -value, the hypothesis is hereby rejected.

Hypothesis 6

Sex-difference of the informal caregivers will not

significantly influence the level of perceived social support of informal caregivers of patients with cerebral palsy.

Test statistics—Mann Whitney U-test

U-value=482.00

P-value=0.14

α -value=0.05

Judgment—since P-value is greater than α -value, I hereby fail to reject hypothesis.

4. Discussion

The study determined the influence of sex-difference on burden of caregiving, social support and quality of life of informal caregivers of patients with CP. It was observed from this study that these sex of the caregivers had substantial influence on the level of burden of caregiving and, physical, psychological, social and environmental domains of their quality of life. However, sex-difference of caregivers had no significance on their level of perceived social support. The influence of gender characteristics on burden of caregiving, social support and quality of life of informal caregivers of patients with CP suggests that gender can predict the level of caregivers' burden, social support and quality of life of informal caregivers of patients with CP, as also reported in other study elsewhere [22]. This agreement might not be unconnected to similarity in study methodology including subject characteristics and similarities in measuring instruments of burden of caregiving, social support and quality of life, among others. Also, variation in total body strength between men and women can be the source of the observed difference in the level of caregiving burden, social support and quality of life of informal caregivers of patients with CP and this by implication affects the execution of some skills requiring physical demands in the caregiving of the patients. Moreover, this could simply reflect the sexual dimorphism, due to the action of sex steroid hormones. Though, mothers and women in general tend to assume the responsibility of caring for children with CP, forgoing other occupational roles [18]. However, the co-morbidities of the children with CP did not influence the burden and quality of life of the caregivers, this is similar to a previous work done by [3]. The functional dependence of children with CP is physically and emotionally overloads family members, especially the mothers, who frequently assume the care provided to these children [26], impeding their inclusion in the job market [8, 18]. Meanwhile, the mothers report that the fathers of children with CP (husband) are an important source of support and help [7] as well as the mothers' own parents [18]. Likewise, [18] also verified that many parents of children with CP found in their own children inspiration to

cope with difficulties when they witness their children's examples of courage and resilience.

In addition, having a friend as a source of social support confirms that caregivers usually seek informal social support sources [2]. Some studies note that friendships usually originate in relationships established with parents of disabled children in the therapeutic environment [8, 18]. In this study, the caregivers also had a high quality of life in all domains; this is similar to the submission of [19]. However, some of the previous studies looked only at an aspect of quality of life or considered overall quality of life instead of taking into account the various domains quality of life such as physical, social, and environment domain [8, 10, 20]. They all concluded that the quality of life of parents with children with CP was low, their study does not align with the findings of the present study. These contrasting findings might also be due to variation in study methodology. Equally, it could also be that the caregivers being aware of the possible outcomes, long-term nature and prognosis of CP once diagnosed, had developed coping strategies that limit the impact of their care-giving on their quality of life. Likewise, in a research by [1], the quality of life domain mean scores of mothers of children with CP were rather modest and comparable to those of mothers of typically developing children. It could be that the mothers of children with CP in that study similarly had access to resources and supports as the same as mothers of typically developing children. Meanwhile, sex-difference of the caregivers in this study had a considerable influence on burden of caregiving of informal caregivers of patients with CP. This is in agreement with the study of [23]. In contrast, the influence of sex-difference of the informal caregivers on perceived social support in the present study was insignificant. This is similar to previous studies by [8, 18, 22].

5. Conclusion

This study therefore concluded that sex-difference of informal caregivers of CP predicts the level of burden of caregiving and all domains of quality of life but cannot determine the level of perceived social support. It is expected that the findings of this study may help clinicians during clinical decision making by enabling them to take into consideration the gender of informal caregivers of CP in the management of patients with CP, thereby enhancing clinical outcome. It was thus recommended that World Health Organization Quality of Life Bref (WHOQOL-Bref), Caregivers Strain Index (CSI) and Multidimensional Scale of Perceived Social Support (MSPSS) measures should be introduced into clinical practice. Also, the clinicians/clinical staff should be trained in using and interpreting the measures.

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