

Burden of caregiving, social support and quality of life of informal caregivers of patients with cerebral palsy

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Abstract. The study investigated the burden of caregiving, social support and quality of life of informal caregivers of patients with CP. 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). The Spearman Rank Order Correlation test was used to test the correlation among the caregivers' quality of life, social support, and burden and some patient and caregiver related variables. The statistical significance was accepted for a p value of <0.05. The outcome of this study showed that the degree of strain on the caregivers was significant, same as the impact on their quality of life. However, the caregivers' level of strain has no significance on their level of perceived social support. Also, majority of the caregivers in this study experienced a considerable amount of burden and the level of perceived social support of caregivers was moderate. The caregivers also had a high quality of life in all domains. It was therefore concluded that caring for a child with CP had significant impact on the level of burden, social support and quality of life of informal caregivers. Also, the informal caregiver had a significant level of burden, a moderate of social support mainly from family and significant others and a high level of quality of life. It was thus recommended that study should be carried out to compare the level of burden, perceived social support and quality of life between informal caregivers of patients with CP and caregivers of healthy children.

Keywords. Care giving, cerebral palsy, social support, quality of life.

Introduction

Despite the progress made in the past to avert or diminish the occurrence of cerebral palsy (CP), the incidence is still on the increase in recent time, and this may be due to poor awareness of CP risk factors and poor health care facility in the background of an

unstable/recessed economic, as treatment can linger for years. Yet, it can be significantly reduced, with millions of lives saved and untold suffering avoided, through early detection/reduction in its risk factors and timely intervention. It has been affirmed that CP is the commonest physical disability in childhood globally (Blair & Watson, 2006). CP is an umbrella term of conditions with enormous 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 (Başaran et al., 2013). Thus, a CP diagnosis brings with it feelings of anxiety and a sense of unpredictability for the parents. In addition, the cause of CP may not be apparent, it is invariably associated with many deficits such as mental retardation, speech and language disorders and oromotor problems (Ones et al., 2005).

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 (Pelchat & Lefebvre, 2004). Caregivers' burden is defined as a strain or load borne by a person who cares for family member with disability (Button et al., 2001). 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 (Almeida & Sampaio, 2007). 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

Received: April 25, 2018 - Accepted: June 7, 2018 - Published: June 10, 2018

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To cite this article: Ahanotu CJ, Ibikunle PO, Hammed AI. Burden of caregiving, social support and quality of life of informal caregivers of patients with cerebral palsy. Turk J Kin 2018; 4(2): 58-64.

DOI: 10.31459/turkjin.418491

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 (Raina et al., 2005). 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 (Wannamaker & Glenwick, 2005). In addition, Brehaut et al. (2004) 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 (Eisenhower & Blacher, 2006).

Furthermore, social support is a multidimensional concept. It 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 (Mastrian et al., 1996). 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 (Kelman et al., 1994). Studies show that the parents of disabled children receive more support from informal sources colleagues (Kelman et al., 1994). In fact, within the area of family and friends, of which the support of the spouse within the family is most important, support (Raina et al., 2005). 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 (King et al., 1999; Greenberg et al., 2006; Feldman et al., 2007).

Equally, 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 (Eker & Tuzun, 2004). Quality of life is usually described as an overall assessment of well-being across various broad domains. Likewise, Okwuruka et al., (2011) 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 (Eker & Tuzun, 2004). 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 (Ones et al., 2005). Fatigue and frequent loneliness lower resistance to stress and disturb the normal regulation of emotions. Quality of life is considered to be influenced by several factors including social, cultural and environmental factors. Several clinical factors are said to influence quality of life and some of the implicated clinical factors include physical, psychological and acute or chronic clinical conditions (Button et al., 2001). It is worth noting that gradients of CP are never the same across communities in the same country and neither are they the same across countries. For this reason the level of burden, perceived social support and quality of life of informal caregivers of patients with cerebral palsy, relationship among the level of quality of life, social support and burden of informal caregivers may not be the same as found elsewhere. The study investigated the burden of caregiving, social support and quality of life of informal caregivers of patients with CP.

Methods

Research Design

This was a correlational survey study of the 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, Amaku Awka, 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 Zimet et al. (1988). 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 to 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 (WHOQOL, 1998) 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. Spearman Rank Order Correlation test was used to test the correlation among the caregivers' quality of life, social support, and burden and some patient and caregiver related variables. 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.

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.

Caregivers' Burden, Social Support, Quality of Life and Some Patient and Caregivers-Related Variable

Table 3 reveals that the burden of the informal caregivers had significant effect on the physical domain ($p=0.002$, $\rho=0.353$), psychological domain ($p=0.001$, $\rho=0.638$), social

domain ($p=0.001$, $\rho=0.376$) and the environmental domain ($p=0.001$, $\rho=0.362$) of their quality, it also had an effect on the total quality of life, ($p=0.001$, $\rho=0.422$). However it had no influence on the total level of perceived social support. ($p=0.30$, $\rho=0.119$) and its domain (significant others $p=0.231$, $\rho=0.137$, family support $p=0.321$, $\rho=0.114$, friends $p=0.687$, $\rho=0.046$).

Table 1

Socio-demographic profiles of participants.

Variable	Category	f	%
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
	Chef	4	5.1
Occupation of Caregivers	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 \pm SD
Age of patient	17.24 \pm 16.06
Age of caregiver	36.54 \pm 6.03
Duration of caregiving	15.40 \pm 9.54
Total caregivers strain index	8.36 \pm 3.75
Physical health domain	54.78 \pm 14.92
Psychological health domain	59.36 \pm 12.50
Social relationships domains	71.76 \pm 17.26
Environment domain	63.36 \pm 14.81
Total quality of life	3.910 \pm 0.71
Significant others	5.37 \pm 1.15
Family	5.39 \pm 1.10
Friends	4.33 \pm 1.38
Total social support	60.40 \pm 10.97

Table 3

Correlation of Caregiver's Strain Index with quality of life and social support.

Variables	r	p
Caregiver's Strain Index vs Physical Domain	0.002	0.353
Caregiver's Strain Index vs Psychological Domain	0.001	0.638
Caregiver's Strain Index vs Social Domain	0.001	0.376
Caregiver's Strain Index vs Environment Domain	0.001	0.362
Caregiver's Strain Index vs Total Quality of Life	0.001	0.422
Caregiver's Strain Index vs Significant Others	0.231	0.137
Caregiver's Strain Index vs Family Support	0.321	0.114
Caregiver's Strain Index vs Friend Support	0.687	0.046
Caregiver's Strain Index vs Total	0.301	0.119

There will be no significant correlation between burden and physical domain of quality of life of informal caregivers of patients with CP ($p > .05$).

There will be no significant correlation between caregiver's burden and psychological domain of quality of life of informal caregivers of patients with CP ($p > .05$).

There will be no significant correlation between caregiver's burden and social domain of quality of life of informal caregivers of patients with CP ($p > .05$).

There will be no significant correlation between caregiver's burden and environment domain of quality of life of informal caregivers of patients with CP ($p > .05$).

There will be no significant correlation between caregiver's burden and perceived social support of informal caregivers of patients with CP ($p > .05$).

DISCUSSION

The study determined the level of burden, perceived social support and quality of life of informal caregivers of patients with cerebral palsy, relationship amongst the burden, perceived social support and quality of life of informal caregivers. It was observed from the study that the degree of strain shown on the caregivers was significant, same as the impact on their quality of life. This is similar with the findings of Okwuruska et al. (2011). However, the caregivers' level of strain has no significance on their level of perceived social support. This is in contrast with the work done by Ones et al. (2005) which showed that the degree of stress experienced by parents of children with CP is not related to the level of their child's degree of functioning, but is rather affected by their access to resources and support and the nature of the family environment.

Moreover, majority of the caregivers in this study experienced a considerable amount of burden. This is in agreement with the study of Raina et al. (2005). Likewise, the level of perceived social support of caregivers in this study was moderate. This is similar to previous studies by Milbrath et al. (2008), Davis et al. (2009), and Pfeifer et al. (2013). Having a friend as a source of social support confirms that caregivers usually seek informal social support sources (Almeida & Sampaio, 2007). Some studies note that friendships usually originate in relationships established with parents of disabled children in the therapeutic environment (Milbrath et al., 2008; Davis et al., 2009). In this study, the caregivers also had a high quality of life in all domains; this is similar to the submission of Okwuruska et al. (2011). 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 (Davis et al., 2009; Eker & Tuzun, 2004; Ones et al., 2005). 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. In a research by Adegoke et al. (2014), 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.

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 (White-Koning et al., 2008), impeding their inclusion in the job market (Milbrath et al., 2008; Davis et al., 2009). Such support is mainly provided by those from the core family (husband, mother, siblings, children), this findings is also similar to the previous works by Button et al. (2001). Meanwhile, the mothers report that

the fathers of children with CP (husband) are an important source of support and help (Button et al., 2001) as well as the mothers' own parents (Milbrath et al., 2008). Likewise, Milbrath et al. (2008) 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.

Conclusion

This study therefore concluded that:

- Caring for a child with CP had significant impact on the level of burden, social support and quality of life of informal caregivers.
- The informal caregiver had a significant level of burden, a moderate of social support mainly from family and significant others and a high level of quality of life.
- There were more female caregivers than male caregivers.

Recommendations

- Further studies should be carried out on the impact of social support (formal and informal support) on children with CP and their caregivers.
- Study should be conducted on other factors that increase burden on the informal caregivers caring for patients with CP.
- Study should be done to compare the level of burden, perceived social support and quality of life between informal caregivers of patients with CP and caregivers of healthy children.

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