

# Cancer Informal Caregivers' Burden At The University College Hospital, Ibadan, Nigeria

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*Abstract: The burden experienced by cancer informal caregivers is enormous. However, little is known about the burden experienced by informal caregivers of cancer patients in Nigeria. Thus the study determined the level of burden among cancer informal caregivers at the Department of Radiotherapy, University College Hospital, Ibadan, Nigeria. It also compared caregivers' characteristics against the level of burden of care and investigated caregivers' feelings of impairment to their health on account of giving care. A questionnaire which consisted of socio-demographic/other variables and the Zarit Burden Interview was administered on 135 consecutive caregivers. Almost half (36.3%) of the caregivers had high level of burden. Relationship to care receiver and intention to continue to give care significantly differentiated caregivers who had high burden from those that had low burden. Eighty six point six percent of caregivers who were above 60 years reported feeling of impaired health sometimes to nearly always while 16.7% of those 20-40 years reported feeling of impairment of health sometimes to nearly always. It is worthy of note that 80% of those who were 18-25 years never had feeling of impaired health on account of caregiving. Experts need to be aware of the burden experienced by caregivers. Spousal and elderly caregivers need to be given attention. They need to be looked after and where applicable evaluated with a view to treating them. As much as possible the elderly may be exempted from caregiving.*

## I. INTRODUCTION

Cancer is linked with high morbidity and mortality (Payne, Smith & Dean, 1999). Owing to the chronic nature of cancer, its debilitating features and the fact that there is some improvement in the treatment, the role of family of informal caregivers in the management is on the increase. For example in the United States health care system, caregivers support therapy like multimodality treatment protocols that are administered in outpatient and home settings (Schumacher, Stewart, Archbold et al., 2008). Caregivers provide support that cut across responding to the physical and psychological needs of the cancer sufferers (Honea, Brintnall, Given et al., 2008). Their roles in the management of cancer patients is totally invaluable.

Caregivers do experience emotional responses to the diagnosis and prognosis of cancer (Given, Given & Kozachik, 2001; Kozachik, Given, Given et al., 2001). In fact the

feelings caregivers undergo or encounter may even be greater than that of the patient (Zabora, Smith, Baker et al., 1992; Yeager, Miaskowski, Dibble et al., 1995). A lot is expected from the caregiver. For example he or she must imbibe novel medical details, inculcate new terminologies, become involve with new treatment situations and must make out time to be with the patient at clinics appointments (Glajchen, 2009). The expectations from caregivers go on. They are expected to make decisions concerning what treatment to adopt. They become the patient's advocate and make decisions. Conflicts can make this decision making difficult and impact on the treatment choices negatively (Siminoff, Rose, Zhang et al., 2006). There may even be family disagreement over which treatment option is most appropriate and this may be a source of burden for caregivers (Fried, Bradley & Towle, 2003).

Caregivers experience difficulties carrying out the demands of providing emotional and physical support for patients and simultaneously meet duties at work and family or

home setting. The imperative to arrange logistics for clinic or hospital visit, home care and insurers may be physically and psychologically tiring for caregivers (Glajchen, 2009). During home care, caregivers arrange and manage home care experts, medical and food provisions. Caregivers may also manage medical emergencies. They assume the patient's domestic responsibilities, run errands and thereby neglect social and work activities. Caregivers have been reported to experience persistent psychological distress and role adjustment difficulties up to 12 months after patient have completed treatment (Northouse, Templin, Mood et al., 1998; Mellon, Northouse & Weiss, 2006).

The burden of caregiving may be worsened when there is strain in the relationship between a patient and a caregiver, poor communication patterns between caregiver and patient and less social support (Gritz, Wellisch, Siau et al., 1990; Lewis & Hammond, 1992; Nijboer, Triemstra, Tempelaar et al., 2000; Kim & Carver, 2007).

Patients may require care for a long time or short time. In many cases caregiving may end with the death of the patient, which may then be followed by the burden of bereavement. Caregivers may have to make burdensome end of life decisions. For example whether to discontinue life support (Haley, Allen, Reynolds et al., 2002).

The duties of a caregiver may sometimes include reporting the symptoms of the patients to the healthcare team. This may be because the patient has cognitive impairment as may be seen in dementia or depression. Hearing impairment may also be a reason why a caregiver may assume the role of reporting symptoms on behalf of the patient. The caregiver may then have to bear the burden of undergoing training needed to accurately assess symptoms (McMillan & Moody, 2003).

It has been reported that the stressors that are particularly burdensome to caregivers are physical care, managing symptoms/treatment, giving emotional support, handling fear and uncertainty about the illness and seeing patients suffer (Hinds, 1985; Stetz, 1987; Carey, Oberst, McCubbin et al., 1991). Assisting a patient with activities of daily living, for example washing and eating may be more stressful than non-personal tasks like shopping (Northouse & Swain, 1987). Comorbidities and cognitive impairment may make caregiving more burdensome (Gagnon, Charbonneau, Allard et al., 2002). The other sources of burden for caregivers are as a result of the fact that caregiving causes disruptions in the caregivers routine and may even affect employment. Second, a sense of lack of support from family members (Stetz, 1987; Blank, Clark, Longman et al., 1989; Weitzner, Haley & Chen, 2000).

Having more social support and personality traits such as optimism and mature coping strategy have been reported to help caregivers to cope while spousal women caregivers have been reported to be vulnerable (Stetz, 1987; Montgomery & Kosloski, 1994; Given & Given, 1996; Wallsten, 2000; Weitzner, Haley & Chen, 2000). The effects of caregiving may be negative physical, financial and psychosocial outcomes (Given, Wyatt, Given et al., 1994; Kurtz, Given, Kurtz et al., 1994; Kurtz, Kurtz, Given et al., 1995; Morse & Fife, 1998; Jepson, McCorkle, Adler et al., 1999; Haley, LaMonde, Han et al., 2001; Kershaw, Northouse, Kritpracha et al., 2004). High level of burden, financial hardship, physical

strain and emotional stress have been reported to be found among cancer caregivers compared to caregivers of patients on management of diabetes or those caring for the frail elderly (Kim & Schulz, 2009). Caregiving has been associated with poor quality of life and risk of dying (Christakis & Allison, 2006; Janda, Steginga, Dunn et al., 2008).

Lower education, lower income, female gender, being unmarried, young age increases caregivers' risk of burden (Lewis, Fletcher, Cochrane et al., 2008; Kim & Schulz, 2009). It is worthy of note that caregivers burden may be less if they sense that treatment team listen to them and consider their opinion concerning the patient's illness, needs and treatment (Emanuel, Fairclough, Slutsman et al., 2000).

Little is known about the burden experienced by informal caregivers of cancer patients in Nigeria. Review of the literature on the burden experienced by cancer caregivers in Nigeria and Sub Sahara Africa revealed paucity of data. A study that evaluated psycho-social and economic burden among caregivers of breast and cervical cancer patients reported that "the financial burden was more problematic than the effects of caring on family routines" (Ohaeri, Campbell, Ilesanmi et al., 1999). Another Nigerian study found that 46.2% and 36.2% of caregivers had severe and moderate levels of burden respectively and the types of burden they suffered were social, physical, psychological and financial. There was a significant inverse association between the burden experienced by caregivers and the patients' functionality. The level of burden increased significantly with the duration of care and there was also significant association between caregivers' burden and wanting to continue giving care (Akpan-Idiok & Anarado, 2014). Yusuf and colleagues reported the mean Zarit Burden Interview score for caregivers to be  $29.16 \pm 12.8$  and found a high level of burden in 49.5% of the caregivers and high level of burden was significantly associated with absence of financial support (Yusuf, Adamu & Nuhu, 2011).

The present study was carried out to address the paucity of data on the burden of cancer family caregivers in Nigeria. Specifically the study determined the level of burden among cancer informal caregivers at the Department of Radiotherapy, University College Hospital, Ibadan, Nigeria. It also compared caregivers' characteristics against the level of burden of care and investigated caregivers' feelings of impairment to their health on account of giving care.

## II. METHODS

The method is akin to a method that is yet to be published. The study was carried out at the Radiotherapy Clinic, University College Hospital (UCH), Ibadan, Nigeria. The study population consisted of caregivers of patients with histologic diagnosis of cancer attending the Clinic. All consecutive 135 caregivers who met the inclusion criteria were included in the study after sample size calculation; using the fishers formula,  $N = Z^2pq/d^2$ . Inclusion criteria were that the caregiver must be 18 years and above, the respective patient must have histological diagnosis and the caregiver must meet the definition of caregiver (American Cancer

Society, 2016) while exclusion criteria were those below 18 years and those that refused to give consent.

The questionnaire consisted of socio-demographic and other variables and the Zarit Burden Interview (ZBI) (Zarit, Reever & Back-Peterson, 1980). The ZBI is used to measure caregivers' burden. It is a likert scale whose score ranges from 0 to 4. It has 22 items and thus the total possible score is 88 while the lowest score is 0. A total score of 0-20 indicates little burden, score of 21-40 indicates mild to moderate burden while total scores of 41-60 and 61-88 imply moderate to severe burden and severe burden respectively. It has been used by other researchers in Nigeria (Walker, Martin & Jones, 1992; Jude, Oladipo & Abiodun et al., 1999) and it has been validated in Nigeria and found to have a reliability coefficient of 0.994 (Akpan-Idiok & Anarado, 2014).

Other ethical considerations included obtaining ethical clearance from the Joint Ethical Review Committee of the University of Ibadan/University College Hospital, Ibadan, observing confidentiality and anonymity, the study was non-invasive and without any harm to the participants. Those who refused to participate were not discriminated against and the participants were assured that they were free to decide not to participate and could choose to discontinue at any point during the process of the interview and that the treatment of their sick one will not be affected.

Statistical Package for Social Sciences (SSPS) was used for data analysis. Frequency, Chi square and Fisher's exact tests were used and the level of significance was set at  $p < 0.05$ .

### III. RESULTS

All 135 questionnaires were analysed and the results are shown in tables 1 to 3.

Level	Frequency	Percentage
High (ZBI score $\geq 21$ )	49	36.3
Low (ZBI score $\leq 20$ )	86	63.7
Total	135	100.0

Table 1: Level of burden of caregivers

Variables	Level of burden		p-value
	High-burden n (%)	Low- burden n (%)	
Gender			
Male	16(32.0)	34(68.0)	0.43
Female	33(38.8)	52(61.2)	
Marital status			
Single	11(35.5)	20(64.5)	0.57
Married	31(33.7)	61(66.3)	
Divorced	4(57.1)	3(42.9)	
Separated	1(50.0)	1(50.0)	
Widowed	2(66.7)	1(33.3)	
Subjective economic status			0.31
low economic class	29(33.7)	57(66.3)	
middle economic class	18(45.0)	22(55.0)	
upper economic class	2(22.2)	7(77.8)	
Educational status			
No formal education	12(36.4)	21(63.6)	0.99
Had formal education	37(36.3)	65(63.7)	
Employment status			

Employed	31(36.5)	54(63.5)	0.96
Unemployed	18(36.0)	32(64.0)	
Relationship to patient			0.04**
Parent	8(33.3)	16(66.7)	
Spouse	13(40.6)	19(59.4)	
Sibling	10(28.6)	25(71.4)	
Others	18(40.9)	26(50.1)	
Availability of helper			0.81
Yes	42(35.9)	75(64.1)	
No	7(38.9)	11(61.1)	
Concerned about cost of treatment			0.11
Yes	44(34.6)	83(65.4)	
No	5(62.5)	3(37.5)	
Had intention to continue care			0.04**
Yes	44(34.4)	84(65.6)	
No	5(71.4)	2(28.6)	
Receives financial support			0.39
Yes	37(38.5)	59(61.5)	
No	12(30.8)	27(69.2)	
Perception of patient's functioning			0.87
Very poor/poor	9(37.5)	15(62.5)	
Fair	16(39.0)	25(61.0)	
Good/very good	24(34.3)	46(65.7)	

\*\* = statistically significant

Table 2: Comparison of caregivers' characteristics against level of burden

Age (years)	Feeling of impaired health		
	Never n (%)	Rarely n (%)	Sometimes to nearly always n (%)
18-25	4(80.0)	0(0.0)	1(20.0)
26-40	21(43.7)	19(39.6)	8(16.7)
41-60	26(38.8)	9(13.4)	32(47.8)
Above 60	1(6.7)	1(6.7)	13(86.6)

Table 3: Comparison of age groups against feeling of impaired health due to care giving

### IV. DISCUSSION

Almost half (36.3%) of the caregivers had high level of burden, that is their score on ZBI was greater than 20. This is quite high, this measure of burden will not only impact negatively on their ability to give care but will also affect their ability to attend to themselves and impair their general level of functioning. However a study carried out at University of Calabar Teaching Hospital, Calabar, Nigeria revealed that 82.4% of caregivers had high burden (Akpan-Idiok & Anarado, 2014). The fact that their study sample provided care for advanced cancer patients may explain the difference in prevalence of high burden. Majority (65.2%) of their care receivers had low functionality. This is likely to impose more burden on their caregivers, since they would have to do much more for the patients. The prevalence rate of high burden found in the present study is similar to the 49.5% reported by Yusuf and his colleagues (Yusuf, Adamu & Nuhu, 2011). Meanwhile.

Relationship to care receiver or patient and intention to continue to give care significantly differentiated caregivers who had high burden from those that had low burden. A high

proportion of spousal caregivers and other (relatives and friends) had a high level of burden compared to siblings and parents. A higher proportion of those who had no intention to continue with care had a high level of burden compared to those who had intention to carry on with care. However Given and colleagues reported that “feeling abandoned (a portion of caregiver burden)” was commoner among non-spouse (Given, Wyatt & Given et al., 2004). There may be a cause and effect relationship between the level of burden and the intention to discontinue care; the high level of burden may cause caregivers to want to discontinue care. However, this study being a cross sectional one is limited with regards to asserting a cause and effect relationship. Other researchers have also reported a significant relationship between burden of care and the desire to continue care (Akpan-Idiok & Anarado, 2014).

A high proportion of female caregivers had high level of burden (Stetz, 1987). A high proportion of those who were widowed, divorced and separated had high level of burden compared to those who were married or single. The least proportion of those who had high level of burden was found among caregivers who were married. Other researchers have found burden to be commoner among female cancer caregivers (Given, Wyatt & Given, 2004; Lkhoyaali, El Haj & El Omrani et al., 2015).

A high proportion of caregivers who self reported themselves to belong to low and middle socioeconomic class had high level of burden compared to those who reported belonging to high socioeconomic class. The level of burden did not differentiate between caregivers who get financial support from those that did not. This is at variance with the finding of other researchers who found high level of burden to be significantly associated with absence of financial support (Yusuf, Adamu & Nuhu, 2011). The proportion of caregivers who had high level of burden between those who had no formal education and those who had was essentially the same. Same thing with the employment status of the caregivers. However, a number of studies have shown that less educated caregivers had more burden and poor overall physical health than better educated ones (Oberst, Thomas, Gass et al., 1989; Weitzner, McMillan & Jacobsen, 1999). It may be that less education is positively associated with lower socioeconomic status and therefore with fewer available resources to deal with the demands of caregiving (Hockley, 2000). In contrast McMillan reported that as the level of education increased quality of life of cancer caregivers decreased (McMillan, 1996).

The availability of helper and concern about cost of treatment did not differentiate caregivers who had high level of burden from those who had low level. One would have expected that if a caregiver had a helper, such a caregiver would have had low level of burden. Similarly, one would have expected that those who had concerns about cost of treatment may have a high level of burden. Maheshwari and colleague found that familiar caregivers with helpers had high burden compared to those that had (Maheshwari & Rajinder, 2016).

A higher proportion of those who reported the care receivers' functioning to be very poor to fair had high level of burden. This may be expected, patients who have poor functioning are expected to require more care. Therefore,

patients with poor functioning would make higher demand on caregivers and consequently cause such caregivers to have a high burden. Other researchers have reported a significant inverse relationship between care receivers' functional ability and level of burden for caregivers (Akpan-Idiok & Anarado, 2014).

The various age groups of caregivers were compared with regard to how much they felt their health had been impaired on account of caregiving. Eighty six point six percent of caregivers who were above 60 years reported feeling of impaired health sometimes to nearly always while 16.7% of those 20-40 years reported feeling of impairment of health sometimes to nearly always. It is worthy of note that 80% of those who were 18-25 years never had feeling of impaired health on account of caregiving. Those who are above 60 years may be less energetic and may suffer from some illnesses that may come with age. These may add to the burden they experience while being a caregivers of a cancer patient. Older cancer caregivers have been reported to experience the highest level of burden (Given, Wyatt, Given et al., 2004).

## V. CONCLUSION

Experts who are involve in the management of cancer patients need to be aware of the burden experienced by caregivers. Spousal and elderly caregivers need to be given attention. They need to be looked after and where applicable evaluated with a view to treating them. As much as possible the elderly may be exempted from caregiving.

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