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Caregivers' Perceptions of Benefits of Caregiving to Advanced Cancer Patients Attending University of Calabar Teaching Hospital, Calabar, Nigeria

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ABSTRACT

Research has reported that caring for patients with advanced cancer is highly rewarding in the midst of the challenges. The aims of the research were to explore the informal caregivers' perceptions and determinants of benefits from caregiving to a relative with advanced cancer attending the University of Calabar Teaching Hospital, Calabar, Nigeria. The research employed a cross-sectional descriptive design. Two hundred and ten (210) eligible caregivers providing care to advanced cancer patients were purposively selected. Data were collected using 17 item Benefit Finding Scale (BFS) and were analysed using descriptive and inferential statistics with the help of SPSS 18.0 and PAS 19.0 software. Caregivers reported substantial benefits from caregiving (M (SD) ranged from 2.93 (1.03) becoming more focused on priorities in the deeper sense of life to 3.60 (0.73) appreciation of life and support from other people on a 1-4 Likert Scale). Caregiver's age, education, religion, marital status and relationship with patients significantly influenced on the level of perceived benefit from caregiving ($p \leq 0.05$). There was a statistical ($p \leq 0.01$) significant relationship between perceived benefits and the desire to continue caregiving. The results suggest that subsequent research should cover caregivers need for interventions to develop problem-focused coping skills and ability to continue with caregiving role.

Key words: Caregivers, perceptions, cancer patients, benefits, caregiving roles

INTRODUCTION

Cancer with a death toll of 8 million persons and 11 million new cases (diagnosis) per year is a leading cause of death worldwide. About 25 million people worldwide are living with cancer (UICC, 2008). Besides the alarming death toll and incidence of cancer worldwide, it is indeed a phenomenon that has caused governments in different countries huge expenditure burden. Between 2007 and 2009, United States of America (USA) spent over \$8.5 million, South Africa and Kenya spent over \$9.2 and 8.6 million respectively (WHO, 2010). In less developed regions, cancer incidence and mortality increased by 56 and 63% respectively in 2008 (IACR., 2008). Nigeria has the highest cancer death rate in Africa (about 10,000 cancer mortality and 250,000 new cases are recorded yearly). The increased incidence of cancer has placed heavy burden on caregiving. The burdens include difficult circumstances, emotions, depressions, among others.

Studies have reported some perceived benefits attributed to cancer caregiving to include: Spiritual growth through prayers to cope with caregiving demands, psychological adjustment in

life in terms of becoming stronger and better, able to manage stress and problems (positive self-view) as well as provision of social support (Moskowitz and Epel, 2006; Kim *et al.*, 2007; Antoni *et al.*, 2010). Other benefits are as follows: Family cancer caregivers can have a sense of personal strength and new possibilities through the experience in the midst of the caregiving challenges, psychological adjustment such as acceptance, empathy, appreciation, family, positive self-view and reprioritization, interventions that enhance their ability to accept their situation and find meaning in their caregiving experience which may improve their satisfaction with life and reduce depression systems (Kim *et al.*, 2007). Caregivers in a psycho-educational intervention group reported gains in the use of positive reappraisal coping and reduction in denial coping. Family caregivers have been reported to accept new possibilities of emotional and spiritual growth, appreciation for new relationship with others and maintaining core priorities in life. Caregivers with high benefit perception have desire to continue caregiving role especially the highly educated ones (Manne *et al.*, 2004; Kim *et al.*, 2007). It has been reported that caring for a patient with advanced cancer has reward such as satisfaction, closeness with the advanced cancer patient and a sense of fulfilling an obligation. Again, positive and negative aspects of caring are associated with psychological well-being and the caregivers' willingness to continue providing care (Balducci *et al.*, 2008).

Nigeria has limited specialized human resources and facilities for cancer care, patients present late at advanced stages of the disease, so the burden of caregiving rests on family members. Again, most traditional cultures in Nigeria justify that families do not need outside help probably due to the following reasons: They do not want to share family matters with others, cannot find the outside help, do not trust social service providers and do not know how hospice care can help them. So the obligatory demands of caring for the sick within the family circuit have many supernatural profits "one good turn deserves another" (Akpan-Idiok, 2013).

Caregivers' perception of benefits used in this study refers to the experience of positive consequences of cancer caregiving. It has been described as the phenomenon of personal growth or positive changes after an encounter with a challenging or traumatic life experience (Kim *et al.*, 2007). However, information on caregivers' perception of benefits of caregiving to people with advanced stage of cancer is relatively scarce, not only in our institution but also in the literature domain in Nigeria. Although, Snapshot study provides limited knowledge of temporal course of 'benefit finding' and the direction of association between 'gains' and the related factors; it will provide a baseline data for subsequent longitudinal studies in the study location. This investigation was therefore designed to: (1) Identify the characteristics of the informal caregivers in University of Calabar Teaching Hospital (UCTH), Nigeria, (2) Elicit the types of benefits from caregiving to advanced cancer patients as perceived by caregivers, (3) Determine the association between caregivers' demographics and their perceived benefits from caregiving, (4) Determine the relationship between the perceived benefits and desire to continue caregiving.

MATERIALS AND METHODS

Cross-sectional descriptive survey design as outlined by Kim *et al.* (2007) and Li and Loke (2013) was carried out among eligible cancer caregivers to obtain a valuable baseline data in University of Calabar Teaching Hospital, Calabar, Nigeria.

Study area/population: The geographical location of Calabar urban is latitude 4°58' North and 8°17' East. It has a common boundary with the Republic of Equatorial Guinea to the south, in the

west, Oron Local Government Area of Akwa Ibom State, in the east Akpabuyo Local Government Area and the North is bounded by Odukpani Local Government Area in Cross River State.

Ethical considerations: The research and ethics committee of the University of Calabar Teaching Hospital, Calabar gave approval for the study and all the participants gave informed consents.

Sample and instrument: Using "A Priory compute power analysis software (G Power 3.1.5) calculator" (Cohen, 1998), 210 respondents were purposively sampled for the study. Validated researcher developed questionnaires and adopted 17 item Benefit Finding Scale (BFS) were used for data collection. This instrument measures the psychosocial attribute of caregiving. Each item is ranged from 1-4 Likert Scale (higher weighted mean score denoting higher perceived benefit for a particular item). The total perceived benefit for a subject is the sum of score in each item where a mean score range of 17-34 indicates no benefits, 35-51 (low benefit), 52-68 (high benefit). Also, caregivers with 6-12 benefits range desired to discontinue care while 13-24 desired to continue caregiving role. The test-retest reliability and face validity of BFS has been established in Nigeria (Walker *et al.*, 1992) and the instrument has previously been used in some studies conducted in the country (Walker *et al.*, 1992; Gonyea *et al.*, 2008). In this study, the reliability coefficient and cronbach's Alpha of BFS were 0.70-0.84 and 0.66-0.91, respectively. Data collection was done in the wards on visiting hours and in the clinics within the hours of 9a.m-2p.m.

Method of data analysis: Analysis of data was carried out using the computer software programme Statistical Package for the Social Sciences (SPSS) 18.0, Predictive Analytical Software (PAS), version 19.0, Descriptive statistics (means, standard deviation and percentages) were used to analyze data and chi-square, simple linear correlation analyses were used to determine the relationships between caregivers' demographics and perceived benefits as well as perceptions of benefits and desire to continue caregiving role.

RESULTS AND DISCUSSION

Socio-economic characteristics of caregivers: In this study, 46.2% of caregivers were within 31-50 age group (mean age = 35.9±18.1), 62.9% were females, 80.0 were Christians, 46.7% were married, 38.6% were unemployed and 62.9% were parents (Table 1). Considering the socio-economic characteristics of the respondents, the informal caregivers were in their youthful and active economic age, mostly Christians, dominated by female and parent caregivers to care receivers. Similar results have been reported by previous researchers (Innes and Payne, 2009; O'Hara *et al.*, 2010; Turkoglu and Kitic, 2012; Akpan-Idiok, 2013).

Types of perceived benefits of caregiving to advanced cancer patients: Table 2 presents means and standard deviations of perceived benefits of cancer caregiving. The types of benefits are categorized into six domains, namely: Acceptance, Empathy, Appreciation, Family, Positive Self-View and Reprioritization. Each domain has numbered items as shown in the Table. Applying 17 item benefit finding scale, the types of perceived benefit by caregiver was appreciation (item 8) with a highest mean of 3.60±0.73; indicating appreciation of life and support from other people. This was followed by item 12, with a mean value of 3.43±0.85, eliciting development of positive self-view and psychological coping skills. Conversely, item 16 had the lowest mean score of 2.93±1.03 reflecting self-realization with a deep sense of purpose of life. Benefit types in this context refers

Table 1: Characteristics of informal caregivers

Characteristics	Frequency	Percentage
Gender		
Male	78	37.1
Female	132	62.9
Age		
<30 years	79	37.6
31-50 years	97	46.2
51-70 years	34	16.2
Mean (\bar{x})	35.9±18.1	
Religion		
Christianity	168	80.0
Muslim	18	8.6
Others	24	11.4
Marital status		
Married	98	46.7
Single	57	27.1
Divorced	12	5.7
Widowed	43	20.5
Educational qualification		
No Formal education	21	10.0
Primary	74	35.2
Secondary	83	39.6
Tertiary	32	15.2
Employment/work status		
Not employed	81	38.6
Artisans	10	4.8
Traders	21	10.0
Farmers	15	7.1
Contractors	4	1.9
Retiree	50	23.8
Civil/public servants	19	9.0
Student/apprentice	10	4.8
Relationship to care receiver		
Parent	132	62.9
Spouse/partner	43	20.5
Sibling	21	10.0
Friend	10	4.8
Brethren	4	1.9

to the positive consequences (gains) of cancer caregiving as reported by the caregiver. Implications of the findings relating to benefit types are that the caregivers derived greater benefits from caregiving given the mean scores especially being appreciated. Similar results were reported by Kim *et al.* (2007) who studied benefits finding in the cancer caregiving experience in United State of America.

Relationship of respondents' demographics and their perceived benefits: The result shows that respondent were female dominated (62.9%) and there was no significant ($p>0.05$) relationship

Table 2: Means and standard deviation of perceived benefits of cancer caregiving

Perceived benefits sub scale	Item	Assertions	Mean±SD
Acceptance (changes in effort to accepting things)	1	I have learnt how to adjust to things I cannot change	2.95±1.00
	2	Helped me take things as they come	3.00±1.09
	3	Shown me that all people need to be loved.	3.24±0.84
Empathy (increase in empathy for all human beings)	4	Made me more aware and concerned for the future of all human beings	3.29±0.85
	5	Taught me that everyone has a purpose in life	3.31±0.91
	6	Made me realize the importance of planning for my family's future	3.11±1.76
Appreciation (changes in appreciation in life)	7	Contributed to my overall emotional and spiritual growth	3.00±1.09
	8	Led me to meet people who have become some of my best friends	3.60±0.73
	9	Helped me become more aware of the love and support available from other people	3.21±0.91
	10	Brought my family closer together	3.29±0.84
Family (family unity)	11	Made me more sensitive to family issues	3.24±0.65
	12	Led me to deal better with stress and problems	3.33±0.78
Positive self-view (psychological coping skills)	13	Taught me to be patient	3.43±0.85
	14	Helped me become a stronger person, more able to cope effectively with future life challenges	3.24±1.12
	15	Helped me realize who my real friends are	3.23±1.05
Reprioritization (self-realization)	16	Helped me become more focused on priorities, with a deeper sense of purpose of life	2.93±1.03
	17	Led me to be more accepting of things	3.25±0.96

NB: Higher the mean score, the greater the benefit derived

between the gender of the caregivers and perceived benefits of caregiving (Table 3). Caregiving may be influenced by gender and by the expected caregivers' roles within the family unit (Levine, 2008). Gender differences did not influence benefit findings but the dominance of females (62.9%) in the study suggested that the female caregivers had trait resiliency to caregiving/challenges in life, so they assumed the role just to fulfill a normative cultural expectations (Yee and Schulz, 2000; Moskowitz and Epel, 2006; Levine, 2008; Freedman, 2012). Obviously, there is evidence of gender inequalities in caregiving, with women being more enmeshed in the role and more exhausted by it, with no positive rewards or gains.

The age group of 30-50 years expressed perception of no (67.1%) and low (72.9%) benefits while a dismal 7.0% informal caregivers at the age bracket (51-70 years) reported high benefit of caregiving. There was also a significant ($p = 0.01$) relationship between age of caregivers and their perceived benefits of caregiving. The implications of the findings with respect to age are that the majority of the informal caregivers were in their active economic age which might be associated with many activities such as attending to their works, social lives and family responsibilities; such busy people may lack trait resiliency and may have difficulty in adjusting to caregiving experience. In contrast, older caregivers derive satisfaction in caregiving because they have positive self-esteem, a variety of skills, resources, problem-solving strategies or good adjustment coping strategies. These findings are upheld by Given and Sherwood (2008) who reported that older caregivers were usually more satisfied with their role than younger caregivers. Kim *et al.* (2007) asserted that older age is associated only with appreciation domain of benefit. Other studies by Moskowitz and Epel (2006), Cameron *et al.* (2002) confirmed that passage of time (in years)

Table 3: Relationship of respondents' demographic and their perceived benefits

Variables	Benefit levels						Total	p-value (\leq)	df = 2 (r-1)(c-1) (3-1)(2-1)	χ^2 cal	χ^2 crit.	χ^2 cal > χ^2 tab reject null/accept alternate hypothesis
	No benefit o e	Low benefit o e	High benefit o e	Total								
Male	35 (29.7)	32 (32.3)	11 (16.0)	78	0.05		4.005	5.99	4.005 < 5.99	Accept the null and reject alt. Hi Not significant		
Female	45 (50.3)	55 (54.7)	32 (27.0)	132								
Total	80	87	43	210								
Age of caregivers												
<30 years	10 (30.1)	39 (32.7)	30 (16.2)	79	0.01							
31-50	52 (37.0)	38 (40.2)	7 (19.9)	97								
51-70	18 (13.0)	10 (14.1)	6 (7.0)	34								
Total	80	87	43	210								
Educational qualification												
Primary education	52 (36.2)	29 (39.4)	14 (19.5)	95	0.05	4	23.177	9.49	23.177 > 9.49	Reject null/accept alternate hypothesis		
Secondary education	20 (31.6)	45 (34.4)	18 (17.00)	83								
Tertiary education	8 (12.2)	13 (13.3)	11 (6.6)	32								
Total	80	87	43	210								
Religion												
Christianity	67 (64.0)	74 (69.6)	24 (34.4)	168	0.46	2	10.05	5.99	10.05 > 5.99	Reject null/accept alternate hypothesis		
Muslim/others	13 (17.4)	13 (17.4)	26 (8.6)	42								
Total	80	87	43	210								
Marital status												
Single	25 (21.7)	22 (23.6)	10 (11.7)	57	0.05	4	29.14	9.49	29.14 > 9.49	Reject null/accept alternate hypothesis		
Married	20 (37.3)	51 (40.6)	27 (20.1)	98								
Divorced/widow	35 (21.0)	14 (22.8)	6 (11.3)	55								
Total	80	87	43	210								

Table 3: Continue

Variables	Benefit levels						Total	p-value (s) (>)	df = 2 (r-1) (c-1) (3-1) (2-1)	χ^2 cal	χ^2 crit.	χ^2 cal > χ^2 tab reject null/accept alternate hypothesis
	No benefit o e	Low benefit o e	High benefit o e									
Employment status												
Not employed	38 (30.9)	30 (33.6)	13 (16.6)			81	0.05	6	8.03	12.6	8.03 < 12.6	Accept the null and reject alt. Hi (not significant)
Artisan/contractor/ student/civil/public servant	14 (16.4)	16 (17.8)	13 (8.8)			43						
Traders/farmers	10 (13.7)	17 (14.9)	9 (7.4)			36						
Retiree	18 (19.0)	24 (20.7)	8 (10.2)			50						
Total	80	87	43			210						
Relation to care receiver												
Parents	53 (50.3)	62 (54.7)	27 (27.0)			132	0.05	4	14.51	9.49	14.51 > 9.49	Reject the null and accept alt. Hi, (significant)
Spouse/partners	15 (16.4)	10 (17.8)	18 (8.8)			43						
Sibling/friend/ brethren	12 (13.3)	15 (14.5)	8 (7.2)			35						
Total	80	87	43			210						

increases positive experience of gains after an encounter with challenging life events like cancer caregiving. However, Manne *et al.* (2004), Antoni *et al.* (2010) upheld that experience of greater benefit is linked to younger age.

The relationship between the educational status of the caregivers and perceived benefits of caregiving was significant ($p = 0.05$) (Table 3). The result showed that a higher percentage (34.38%) of the highly educated ones perceived high benefits from caregiving. So less education predicts less satisfaction. The perception of benefits can be attributed to the caregivers' level of education. This could be explained by the finding that the highly educated caregivers incurred financial strains due to caregiving expenses, they failed to derive self-esteem from caregiving and developed poor adjustment strategies. This finding is not however conclusive; some studies by Kim and Given (2008) upheld that caregivers with lower levels of education do report more satisfaction from caregiving. Reported that lower education-income status has been linked to benefit experience but another study found more benefit finding among those with more education (Sears *et al.*, 2003).

There was also a significant relationship ($p = 0.46$) between religion and perceived benefits of the caregivers (Table 3). Religion variable and respondents' caregiving benefits experience are significantly related. This implies that one's religion could provide the basis for providing care to advanced cancer patients spirituality therefore acts as a supportive coping strategy for cancer informal caregivers in performing their caring roles. This is consistent with Kim *et al.* (2007) who stated that religious coping intervention like the use of prayer among informal cancer caregivers would relate to benefits perceptions.

There was also a significant ($p < 0.05$) statistical relationship between the marital status of the caregivers and their perceived benefits by caregiving (Table 3). The result shows that except for the married ones, majority of those who expressed no and low benefit were either single or divorced/widowed. Indeed, in this research, marital status of informal cancer caregivers' are associated with their caregiving benefit experiences. This implies that spouses of care receivers might perceive some benefits in caregiving than the others for some reasons such as increased bond of love between them at such moments in their relationships. Kim *et al.* (2007) found that husbands reported an experience of benefit finding 1-5 years after their wives breast cancer diagnosis, although at lower levels than their wives did. These findings were replicated with partners of breast cancer survivors who were >18 months post diagnosis (Manne *et al.*, 2004; ACS, 2007). Also, wives of men with prostate cancer also reported positive gains of caregiving (Carver and Antoni, 2004). There was no significant ($p > 0.05$) statistical relationship between the caregivers' employment status and their experience of benefits from cancer caregiving (Table 3). Among the 210 caregivers, 81 were not employed, 68 of them reported no or low benefit of caregiving. Only 13 respondents

Table 4: Distribution of respondents based on the weighted mean scores of the perceived benefits and desire to continue caregiving, n = 210

Variables	Benefits/desire	Weighted mean scores range	Frequency	Percentage
Benefit level	No benefit	17-34	80	38.1
	Low benefit	35-51	87	41.4
	High benefit	52-68	43	20.5
Total			210	100.0
Caregivers' desire	Not to continue	6-12	87	41.4
	To continue	13-24	123	58.6
Total			210	100.0

Table 5: Cross tabulation of respondents perceived benefits of caregiving and desire to continue with caregiving role

Benefits range score	Perceived benefits	Caregivers' desire to continue caregiving		Total
		Not to continue (6-12)	To continue (13- 24)	
17-34	No benefit	80 (100%)	0 (0%)	80
35-51	Low benefit	7 (8.05%)	80 (91.95%)	87
52-68	High benefit	0 (%)	43 (100%)	43

Table 6: Perceived benefits and desire to continue caregiving simple linear correlation analysis of relationship between perceived benefits and desire to continue caregiving

Variables	$\Sigma x \Sigma x^2$	$\Sigma y \Sigma y^2$	Σxy	rxy	p value (\leq)
Perceived benefit (xi)	394.3	78391		0.65	0.01
Desire to continue caregiving (yi)	9275	444353	181120	0.65	

$$r = \frac{\sum xy}{\sqrt{\sum x^2 \sum y^2}} \text{ where, x: Perceived benefits y: Desire to continue caregiving}$$

perceived high caregiving benefits. The remaining 129 cancer caregivers who were engaged in one work or the other related their benefit experiences as high, low and no benefit, respectively. Caregiver's employment status was not significantly related to the respondents' experience of cancer caregiving gains. Kim *et al.* (2007) has confirmed that employment and income status did not relate to benefit experience in cancer caregiving.

Perceived benefits and desire to continue caregiving: Although, majority (61.9%) of the informal cancer caregivers reported to have derived perceived benefits from caregiving (58.6%) had the desire to continue in caregiving role (Tables 4-5). Also, there was strong and positive relationship ($p = 0.01$) between perceived benefits and desire to continue caregiving (Table 6). In cancer caregiving, positive experiences of providing care relate to caregiving role continuity. High positive experiences of caregiving serve as positive predictors of role continuity while low positive experiences are the reverse (Kim *et al.*, 2007). Similar results were obtained by earlier researchers on the perception of benefits (Thornton, 2002; Kim *et al.*, 2007).

The result shows that there was a ($p = 0.05$) statistical significant association between the relationship to care receivers and their caregiving benefits perception (Table 3). More parents perceived low and no caregiving benefit with spouse and partners leading the list with high benefit cancer caregiving perceptions. Among the siblings, friends and brethren, very few respondents perceived cancer caregiving as rewarding. The statistical significant association between the relationship to care receivers and benefit perceptions suggests that spouse and partners could develop significant lifestyle changes due to cancer caregiving experience. For instance, proactive practice of healthy behaviours in a culturally acceptable manner in terms of increased exercise, better diet and screening awareness are some benefits of cancer caregiving (Kim and Given, 2008; Golant and Haskins, 2008). On the other hand, Beach *et al.* (2000) upheld that increased help provided to one's spouse has been related to decrease in anxiety and depression. This indicates that caregiving is a rewarding experience. Nevertheless, Kim *et al.*, (2007) reported that spousal status did not relate to any benefit finding domain of caregiving.

Spousal caregivers for cancer patients experience various positive aspects of caregiving like enhanced relationship with the care receiver, the feeling of being rewarded a sense of personal growth and a perception of personal satisfaction. Also, daily enrichment events and self-efficacy on

the part of the caregivers' were identified as the determining factors in the positive aspects of caregiving. All the domains of the positive aspects of caregiving are interdependent and worked together to contribute to the positive outcomes experienced by spousal caregiving.

CONCLUSION

The research has provided significant information on informal caregivers taking care of advanced cancer patients in University of Calabar Teaching Hospital, Calabar, Nigeria. Caregivers' socio-demographics (gender, age, education, religion, marital status and relationship to caregivers) were strong predictors of cancer caregiving benefits. Some of the caregivers reported experiencing benefits from providing care to cancer patients. Such growth experiences were pronounced in the domain of appreciation, eliciting appreciation of life and support from the people, subscale of positive self-view, highlighting development of positive self-view and psychological coping skills and increase in empathy for all higher beings. From the study, the higher the gains of advanced cancer caregiving experienced by the caregivers, the greater the desires to continue caregiving role. The findings suggest that subsequent studies should measure on caregivers need for interventions to develop problem-focused coping skills and ability to continue with caregiving role. A specially designed intervention programme to enhance the desire to continue caregiving will support spouses caring for advanced cancer patients in the study area.

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