

QUALITY OF LIFE AND COPING STRATEGIES OF UNPAID CAREGIVERS OF HYPERTENSIVE PATIENTS

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Abstract

Background: Quality of life (QoL) is an important outcome in management of patients and their caregivers. Use of coping strategies by caregiver may influence his or her quality of life.

Objectives: The main objective of this study was to assess the quality of life and coping strategies of caregivers of hypertensive patients and to examine the determinants of QoL.

Methods: This study was a cross-sectional survey. This study verified the quality of life and coping strategies of caregivers of hypertensive patients using a self-administered questionnaire. The study was conducted in Federal Medical Centre Lokoja. Respondents were all the unpaid caregivers taking care of hypertensive patients on admission. Validated questionnaires (Adult Caregiver Quality of life questionnaire, ACQoL and Stress Coping) were used to collect information from these caregivers. The questionnaires were sorted. Domains of the questionnaires were coded and analyzed using the IBM SPSS version 21.0 for windows. Results were presented as frequency and mean \pm standard deviation.

Result: A total of two hundred and fifteen (215) caregivers completed the questionnaires. Over half of the caregivers were males 116(54.0%). About 29(13.5%) reported 'low self esteem' due to the nature of the caring activities. About 69.3% of the caregivers reported that their patients were dependent on them to perform most of their activities. The satisfaction of the care givers was influenced by duration of patients' illness, employment status, and co morbidities. Confiding in someone had a positive outcome on the quality of life of the caregivers. Emotional focused (avoidance and blaming others) was the major coping strategy employed by the caregivers. This coping strategy has been known to have a negative impact on their quality of life.

Conclusion: The caregivers had low quality of life with high stress levels. Emotional focused was the major coping strategy employed by the caregivers. Increasing age of the caregivers,

unemployment status, female gender, low education level, presence of health problems, duration of care above four weeks had negative impact on their Quality of life.

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Introduction

The role of caregivers is crucial in providing support to patients. Caregivers are normally used to refer to unpaid relatives or friends of a disabled or an ill individual who helps that individual with his or her activities of daily living (Aaronson et al; 2013). A general definition of a caregiver is someone who is responsible for the

care of someone who has poor mental health, physically disabled or whose health is impaired by sickness or old age. Caregivers often shoulder the principal, multifaceted responsibilities of long-term disability management (Baronet A. 2019). One of the main challenges for caregivers is to manage their patients' chronic health problems effectively while maintaining the requirements of everyday living. In some cases, the provision

of such care can prove detrimental to both the physical health and the psychological well-being of caregivers of patients with chronic disabilities and have an impact on family income, family functioning, and sibling adjustment (Gallacher et al; 2017). In the past three decades, tremendous changes in health care systems have exerted a shift toward outpatient community and home-based settings, which in turn have increased the responsibilities of informal caregivers. In addition, several factors that may contribute to the perceived burden and stress experienced by caregivers of patients with disabilities exist. These factors include smaller family units, increased rate of marital breakdown, technologic innovations, and pharmacologic advancements in medicine (Brouwer et al; 2018).

As established by Nigeria's census result online, there are about 881,579 caregivers. Of these, 275,969 are reported to provide more than 20 hours of care a week, and 24% provide more than 50 hours of care. Caregivers who provide care for 20 hours a week or more are regarded as being at the 'heavy end' of caring. This assumes that they are the most involved caregiver, providing both personal and physical care, resulting in high level of stress and most in need of support services (Elliot et al; 2010). Also, caregivers in Nigeria are regarded as 'partners in the provision of care. As a result, support services provided to caregivers are regarded as part of the overall package of care to the person being looked after (Brouwer et al; 2018)..

In Taiwan, 600,000 caregivers spent an average of 13.55 hours a day care giving. 80% of these 600,000 caregivers encountered limitations on social activities while 70% of them needed to take care of patients even when they did not feel well. Among these caregivers, some of them suffer from guilt, depression, nervousness, injuries, sleeplessness and

hopelessness (Cohen et al; 2002). Thus it is very essential task to promote the capabilities of caregivers and improve their quality of life (Barone; 2019).

In the United States, according to a 2010 survey on care giving, the amount of satisfaction with care giving is directly related to the type of disease from which the care recipient suffers. Caregivers of depression sufferers, cancer and cardiac disease have more difficulty than those caring for patients who suffer from diabetes, high blood pressure and arthritis (Donorfio et al; 2010).

It is well established that caring for someone has negative effects on both the mental and physical health of the caregiver. In a systematic review of the literature, it was found that the only variable consistently found to predict caregivers' burden was the level of patients' symptoms (Donorfio et al; 2010).

There is weak and conflicting evidence about the role of other illness-related and demographic characteristics on caregivers' experiences as well as the effect of social support and feelings of mastery. In order to develop interventions to reduce caregivers' distress, it is important to identify modifiable elements related to the care giving role. Caregivers' appraisals about the experience of care giving may be potential areas to target (Cohen et al; 2013).

High levels of burden are related to deterioration of the caregiver's quality of life, which has been shown to adversely affect many aspects of the patient's recovery (Baronet et al;

2019). Providing caregivers with support therefore may not only improve the caregiver's quality of life but the patient's quality of life as well. There is no consensus over the definition of 'quality of life'. Indicators of quality of life that have been suggested in the literature are perceived health status, coping strategies and satisfaction with life (Grant et al; 2010).

Health care professionals are now realizing that family caregivers are indeed "second-order patients" who are in need of care and support (Arno P. et al; 2019). Although family caregivers serve as members of the care giving team, they too must be recipients of palliative care. Palliative care, as a philosophy of care, provides a combination of active and compassionate therapies intended to comfort and support patients and families who are living with illness (Becker, S; 2018).

Because patients and their family caregivers have an interdependent relationship, healthcare professionals need to treat the patient-caregiver dyad as the unit of care (Becker, S.; 2018). Research indicates that the more we, as healthcare professionals, help caregivers, the more

we will help patients (Becker et al; 2018). Treating them together creates a synergistic effect that is stronger than treating the patient alone (Brouwer et al; 2018). In addition, many nursing interventions (e.g., those promoting more effective pain management) are likely to be more effective when they are offered jointly to patients and caregivers and when dyads are encouraged to work together to manage problems related to the illness (Cohen et al; 2015).

Family caregivers face multiple demands as they care for their loved ones with illness, and these demands have increased dramatically in recent years. Patients with cancer now receive toxic treatments in outpatient settings and return home to the care of their family members. Some patients receive in-home infusions, which were unheard of a few years ago. Family caregivers provide tasks that were previously provided by nurses; however, caregivers lack the educational preparation that nurses receive (Carver et al; 2019).

Family caregivers also lack the support they need to deal with their own emotional distress. Family caregivers reported receiving less support than patients (Chao et al; 2010). Although the illness is not in caregivers' bodies, its impact affects their lives and all aspects of their quality of life. Family caregivers are co-sufferers who also need support (Cosway et al; 2010).

Having a well-prepared, confident family caregiver is beneficial. Research has documented that when caregivers feel more confident in providing care, patients have better symptom management, spend less time in bed, have more energy, and have higher physical quality of life (Chao et al; 2010). In addition, more confident caregivers facilitate better patient medication management, and have less fatigue themselves, less caregiver strain, and more positive moods (Brouwer et al; 2019). It was also discovered in a study to examine the level of burden and extent of support on family caregivers of people living with aids in Calabar, south east Nigeria, that caregivers experienced high level of burden and limited support.

Objective: The objective of this study was to determine the quality of life and coping strategies of unpaid caregivers of hypertensive patients in a tertiary hospital in Nigeria and to examine the determinants of quality of life.

METHODS

Study design

This study was a cross-sectional survey research design. This is because the study verified from the respondents their quality of life and coping strategies as at the time of administration of the questionnaire.

Study area

The research was carried out in Lokoja city. Lokoja lies at the confluence of the Niger and Benue rivers and is the capital of Kogi state in Nigeria. The Federal Medical Centre in Lokoja was chosen as data collection centre.

Sample size

The population of the study comprised of all the caregivers taking care of hypertensive in-patients in the hospital. All the caregivers who met the inclusion criteria were used for the period of this study (January 2018 – October 2018).

Study subjects

The study subjects were caregivers who fulfilled the following inclusion criteria.

The inclusion criteria for care givers were:

- Those who provide care for 20 hours a week or more to hypertensive patients. This assumes that they are the most involved caregivers, providing both personal and physical care.
- Those who manage medications or talk to doctors and nurses on behalf of these patients
- Those who help bathe or dress hypertensive patients who is frail or disabled
- Those who take care of household chores, meals or bills for hypertensive patients who cannot do these things alone.

The exclusion criteria for caregivers were:

- Those who are below 18 years of age
- Those who are not fluent in spoken and written English

DATA COLLECTION

Non-participation and non-responsiveness were low in this study due to face-face administration. This mode of administration ensures data completeness, and enables appropriate interpretation of the questionnaire. In this study, this administration mode was chosen due to the difficulty in retrieving addresses from the patient and their caregivers and also to circumvent the possible issue of non-response.

Validated questionnaires were used in this study. Two questionnaires (Adult caregiver Quality of Life questionnaire and stress coping questionnaire) were administered to the caregivers.

Also each participant was required to fill a form to capture their demographic data. Each participant was required to fill these questionnaires with little or no assistance from the research pharmacist.

DATA ANALYSIS

Data were collected over a six months period from January 2018 to October 2018. Questionnaires were sorted. Items/Domains of completed questionnaires were coded and entered into the 2007 Excel package. Descriptive statistics (percentage, mean and standard deviation) were calculated using SPSS version 16.

Pearson correlation was used to examine correlation between coping strategies and quality of life. Spearman's correlation was also used to examine correlation between coping strategies and each dimension of quality of life. Problem focused coping and emotion-focused coping were compared according to sex by t-test.

ETHICAL CONSIDERATION

Approval for the study was obtained from ethical committee of Federal Medical Centre Lokoja and verbal informed consent was obtained from care-givers. The study was at no cost to the participants and information from the participant were kept strictly confidential

RESULTS

Demographic Characteristics of Caregivers

The caregivers were predominantly males 116(54.4%) and 112(52.1%) of the caregivers were above 40 years, About 204(95%) have a formal education with about (203)94.4% earning a monthly income above 10,000 naira. 161(74.9%) of the care givers were family members while 54(25.1%) were hired/paid. 23(10.7%) of these care givers were students, 109(50.7%) were employed, 74(34.4%) were unemployed while 9(4.2%) reported to have been retired from active service [Table 1]. Also 192(89.3%) of these care givers said they have never smoked before. 29(13.5 %) of the caregivers reported to have low self esteem due to caring while 149(69.3%) had their patient dependent on them for most of their activities. Also in this study, duration of patient's illness, employment status and co morbidities influenced the care giving satisfaction derived by these caregivers [Table 1].

TABLE 1: DEMOGRAPHIC DATA OF CAREGIVERS N=215	
DEMOGRAPHIC	CAREGIVERS (n%)
Age	
<20	6(2.8)
20-30	24(11.2)
30-40	72(33.5)
>40	112(52.1)
Sex	
Female	98(45.6)
Male	116(54.4)
Relationship	
Family member	161(74.9)
Hired	21(9.8)
Student	23(10.7)
Single	34(15.8)
Level of education	
No formal education	9(4.2)
Formal education	106(49.3)
Monthly income (naira)	
<10,000	12(5.6)
10,000-20,000	98(45.6)
20,000-30,000	72(33.5)
>30,000	28(13.0)
Occupation	
Employed	109(50.7)
Unemployed	106(49.3)
Smoking status	
Yes	28(13.0)
No	192(89.3)
Self Esteem	
High	125(58.1)
Low	29(13.5)

Table 1: DEMOGRAPHIC DATA OF CAREGIVERS N=215

SQuality of Life of Caregivers

The care givers overall quality of life was slightly above

average 60.67 (average is 60 and above) and majority of them reported to have less support for caring(8.54±2.59), less caring choice(6.51±2.78), more caring stress(6.47±2.38), financial constraints(5.97±2.99), problem with personal growth(8.49±2.25), low sense of value(7.73±1.66) and low caregivers satisfaction(7.95±1.41) [Table 2].

Characteristics	N=215	Mean± Standard deviation
Demographics		
Number of absences from school/week		1.07±0.88
Duration of caregiving		2.67±4.69
Family size		4.61±2.28
Quality of life		
Support for caring		8.54±2.49
Caring choice		6.51±2.78
Caring stress		6.47±2.38
Money matters		5.97±2.99
Personal growth		8.49±2.25
Sense of value		7.73±1.66
Ability to care		9.01±2.15
Caregivers satisfaction		7.95±1.41
Caregivers overall QoL		60.67±7.67
Overall QoL(%)		50.38±6.39
Coping strategy		
Problem solving		10.22±1.75
Social support		10.17±1.83
Avoidance		10.18±1.83
Blaming others		10.19±1.96

Table 2: QUALITY OF LIFE AND COPING STRATEGIES OF CAREGIVERS

Coping Strategies Employed by the Caregivers

It can be deduced that majority of these caregivers employed more of emotional-focused coping strategy (avoidance and blaming others) to problem-focused coping strategy (problem solving and social support) [Table 2].

Relationship Between Quality of Life and Coping Strategies

It can be deduced that caregivers who employed emotional-based coping strategy (avoidance and blaming others) reported to have a very low quality of life while the few of them who employed problem focused coping reported a mid-range and high quality of life [Table 2].

Also caregivers who had high caring stress, low satisfaction derived from care giving, financial constraints and low self esteem were seen to employ more of emotional-based coping strategy [Table 2].

DISCUSSION

Less support for caring, financial constraints, problem with personal growth and low sense of value can lead to more caring stress and perceived low caregivers satisfaction. It was observed that caregivers who had high caring stress, low satisfaction derived from care giving, financial constraints and low self esteem were seen to employ more of emotional-based coping strategy.

Caregivers above the age 40years reported low quality of life and high caring stress irrespective of their sex while most of the caregivers below the age 40years reported that they had low self esteem when they were asked to rate their self esteem. Even though low self esteem could be caused by some many factors besides age, it was peculiar to young caregivers used in this study.

Majority of the caregivers reported high caring stress and poor

satisfaction derived from their new role. This in turn could have effect on the overall quality of life of their patients as it can be seen that patient of these caregivers rated their health to be poor and also blamed their ill health on a person. This in turn could affect medication compliance thereby increasing the patients stay in the hospital (Chao et al; 2010)

Also a high workload often has ripple effects on caregivers' wellbeing, acting as a primary stressor that may be aggravated further by limited resources. Caregivers reported the high workload as their most stressful daily challenge. This often resulted in the caregiver losing a sense of control and certainty. This significant finding supports existing evidence that a high workload often places the individual in a vulnerable position as they experience the additive effects of increased stress (Fortune et al; 2010). The additive effect may have a significant effects on an individual caregivers health. For these and many other reasons, the World Health Organization has defined addressing the needs of family and family caregivers as one of the primary objectives of palliative care (WHOQoL Group; 2015).

This findings reveals necessity of the stress management techniques to be taught to both patient and their caregivers. We can also see from the result that under stress, caregivers and patients do not feel like mixing or socializing with others. They may not want to discuss their problems with health workers and others and in their attempt to be alone; they keep themselves away from others as much as possible. During this transitional period, the easiest strategy seems to be denial of the stressful event or deal with it by an emotional response.

Access to relevant and timely information also influenced the caregivers ability to cope. When caregivers were able to access information early in their patients, the reported to have felt prepared for what they might encounter as the care giving proceeded and were secure with this knowledge at hand. Information on how to care for the patient (example bathing, toileting, feeding and managing pain) and on the health and social services that were available to them was most relevant useful in helping them cope.

A meta-analysis revealed emotion-focused strategies are often less effective than using problem-focused methods in relation to health outcomes (Cohen et al; 2011). In general people who used emotion-focused strategies such as eating, drinking and taking drugs reported poorer health outcomes. Such strategies are ineffective as they ignore the root cause of the stress. The type of stressor and whether the impact was on physical or psychological health explained the strategies between coping strategies and health outcomes (Cohen et al; 2011).

CONCLUSION

It is the conclusion of this study that caregivers of hypertensive patients experienced a low quality of life due to increased caring stress which could be as a result of unemployment or low income,

increased duration of caring or their own diagnosed health problems. Majority of the caregivers reported to have employed emotion-focused coping rather than problem-focused coping and most of these patients who employed emotion-focused coping as a way of coping with stress reported a low quality of life.

Finally, having a well-prepared, confident family caregiver is beneficial. When caregivers feel more confident in providing care, patients have better symptom management, spend less time in bed, have more energy, and have higher physical quality of life. In addition, more confident caregivers facilitate better patient medication management, and have less fatigue themselves, less caregiver strain, and more positive moods.

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Conflict of Interest: The authors declare that there are no conflict of interest.

Data Availability Statement: All the data from this study have been included in the article. Additional data can be provided upon request.

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