**FACTORS INFLUENCING BURDEN OF PALLIATIVE AND END OF LIFE CARE AMONG INFORMAL CAREGIVERS OF PEOPLE WITH CANCER IN A TERTIARY HOSPITAL, PORT HARCOURT, NIGERIA**

**Abstract**

Informal caregivers are pivotal in the care of people having advanced cancer and other chronic illnesses. Their roles cannot be over emphasized as they are involved in patients’ care in and out of the hospital environment. Most patients during palliative care and towards death rely on informal care providers for support to perform most activities and attain life quality. This study therefore, assessed the factors influencing burden and perceived effects of palliative and end of life (PEOL) care among informal caregivers (ICG) of people with cancer (PWC) in a tertiary hospital in Port Harcourt. This study adopted a cross-sectional design. Two hundred and seventy, three informal care givers of people with cancer in the tertiary hospital were selected by convenience sampling technique. A standardized questionnaire was used to obtain data on level of burden, while a validated self-structured questionnaire was used to collect data on factors influencing burden and perceived effects of burden. Factors influencing burden were identified using descriptive statistics. To determine perceived effects of care burden; mean, standard deviation and range was used and the strength of each perceived effect was determined by the mean score. Care recipient dependency (Mean 8.61, std 1.46, rang 7), social support (mean/std 6.93±1.23, rang 5) and financial factors (Mean 8.83±2.21, rang 7) were identified as factors influencing care burden. Perceived effects of burden on respondents were mostly psychological (mean=13.20) and physical (mean=11.21) effects. It was recommended that health care professionals assess unpaid care providers of patients with advance cancer for burden and its effects.

**Keywords:** Factors, Informal care givers, Influencing factors of burden, Palliative, End of life care

# Introduction

Cancer is a significant contributor to the high death rate worldwide. It is an anomalous growth that remains unaffected by the body's immune system owing to its distinct characteristics. Cancer cells may spread to other tissues via the bloodstream, affecting many organs (metastasis) and potentially resulting in death. Relatives have a significant role in caring for cancer patients, particularly during the final stage. However, some health professionals fail to acknowledge their efforts, leading to a lack of emphasis in their well-being (MuliiraaIrene & Kizza, 2019).

In 2020, Cancer caused 10.3 million deaths and resulted in 19.3 million new cases globally, ranking it as the second leading cause of death (WHO, 2021). The number of new cases is projected to rise to around 27.5 million worldwide by 2040 (American Cancer Society, 2021). Nigeria has around 124,818 cancer cases, with 100,000 new cases reported year and a death rate of 78,899 (Nigeria - Global Cancer Observatory 2020). The rising cancer rates, limited hospital resources, longer inpatient stays, high treatment costs, and societal expectations of family care have led to increased involvement of informal carers in the support of patients with cancer during palliative and end-of-life care. Informal carers offer around 70%–80% of in-hospital and out-of-hospital care for individuals with cancer (Onyeneho and EIlesanmi, 2021). Informal carers in the European Union (EU) provide 60% of all care, which has been shown to be more costly than official care.

Informal carers internationally, particularly those caring for cancer patients, are experiencing worrying levels of burden. According to the National Cancer Institute (2019), informal carers of cancer patients experienced 50% emotional stress and 25% financial stress. These stressors can lead to physical illness, anxiety, depression, sleep disturbances, poor concentration, reduced income and assets, debts, challenges in paying household bills, and potential bankruptcy. Family carers in sub-Saharan Africa caring for advanced cancer patients in stages 3 and 4 report severe to very severe pain at a rate of around 73.1% (Akpan-Idiok et al., 2020).

Anxiety was found in 35.2% of cases, with 20% experiencing severe levels of anxiety. Depression was reported in 48.2% of cases, with 27.5% experiencing extremely significant depression (MuliiraaIrene and Kizzab, 2019). Mishra et al. (2021) found that 70.22% of informal carers in India had a lower burden, whereas 21.38% had a greater burden. Zuo et al. (2020) did research in West China which revealed a high burden score of 53.18 among informal carers. The duration spent providing care had the highest mean score of 14.28 ± SD, followed by burden on development (13.65), physical health burden (10.52), social burden (7.61), and psychological burden (7.12). Patients at the advanced stage of cancer exhibit many signs and symptoms, necessitating more care from informal carers, hence escalating the strain on them. National Cancer Institute (2019) reported that carer load is around 55.6% and is linked to depression and religious coping.

Carer burden is the stress or weight experienced by an individual who looks after a family member who is chronically sick, handicapped, or old (Mishra et al. 2021). Zhu et al. (2020) described informal carer load as the complex pressure experienced by carers when looking after a family member or loved one over an extended period. Hiseman and Fackrell explained that informal carer load arises from a mix of several stresses that might be overwhelming, leading to observable or felt symptoms.

Informal caregivers take on various responsibilities such as providing physical and emotional support, administering medication, handling household tasks, offering financial assistance, identifying and reporting symptoms and side effects, and accompanying the patient to medical appointments. Possible extra duties may include advance care planning, urgent and vigorous efforts to alleviate suffering, symptom management, important decision-making, and acting as a surrogate (Cancer Net 2019). These responsibilities can lead to an unbearable stress referred to as carer load. This stress can manifest as various psychological or physical issues, ultimately affecting the well-being of both the patient and the carer. According to the World Health Organization (WHO) in 2021, one out of every four informal carers providing intensive long-term care for chronically ill individuals experiences stress due to the growing care responsibilities and the difficulty of balancing care duties with household responsibilities (Lindt et al., 2020). Statistics from Nigeria and other developing nations indicate that individuals providing informal care to cancer patients are at risk of experiencing various psychological and physical burdens that can harm their overall health. These burdens include burnout, higher mortality rates, weight loss, weakened immune system, and insomnia. (Ogunyemi et al., 2021). Jite et al. (2021) found that 72% of informal carers in Nigeria feel burdened, and around 46.3% of those caring for cancer patients in Lagos felt overwhelmed, particularly those without assistance. In a study conducted in Nigeria in 2014, it was found that informal carers of cancer patients experience significant burden, with physical burden being the most prevalent at 46.7%, followed by financial burden, social burden, and minimal psychological burden at 25.6%, 17.5%, and 10.2% respectively (Akpan-Idiok and Anarado, 2014). Comparing the results of investigations conducted in 2021 and 2014, which are about 6 years apart, it is evident that there have been few changes. Gaps persist in understanding the challenges experienced by unpaid carers of cancer patients in some locations of Nigeria, including Port Harcourt (Ogunyemi et al., 2021; Agbonjimi et al., 2022; Gbenga-Epebinu, et al., 2022).

Moreover, the growing responsibility of informal carers in patient care and the lack of attention given to their unmet needs by health professionals and facilities necessitate further research to examine the burden and its impact on the overall well-being of informal carers. Early diagnosis and care by health professionals are crucial for averting problems (Bocharov & Shishkova, 2021).

The researcher observed that informal care givers in study area are massively engaged with the care of their sick relatives as they can be seen in and around the hospital carrying out one activity or the other relating to patient care (getting drugs, paying hospital bills, accompanying sick relatives etc.) and some complained about being stressed out. Based on these observations and cancer being one of the chronic diseases requiring informal care, the researcher sought to assess the factors influencing burden and the perceived effects of palliative and end of life (P & EOL) care among informal caregivers (ICG) of people with cancer (PWC) in a tertiary hospital in Port Harcourt, Nigeria. The specific objectives were:

1. To identify factors influencing burden of palliative and end of life care among ICG of PWC in a tertiary hospital in Port Harcourt, Nigeria
2. To determine the perceived effects of burden among ICG of PWC during palliative and end of life care in a tertiary hospital in Port Harcourt, Nigeria.

**Literature Review**

**Factors Influencing Informal Caregivers Burden**

Annisa (2018) categorised factors affecting informal carer load as internal and external variables. Internal variables affecting carer load include socio-demographic characteristics such as gender, age, religion, culture, marital status, education, employment, income, connection with the patient, and number of family members. External considerations include the duration of care for the patient and perceived social support.

Bursack (2021), found that carer circumstances, care recipient characteristics, and overall situation factors are all associated with the burden of caregiving. Carer circumstances include age, health status, number of hours provided daily, and duration of care. Care recipient characteristics include age, functional status, dependency, and stroke duration. Overall situation factors include the number of individuals involved in the care and support system. When the care recipient's functioning is low and requires more care hours, the burden is exacerbated by the time it takes to provide that care. The caregiver's physical and mental well-being is affected by the reduced functional abilities of cancer patients. Family carers often do not have enough time to rest, leading to feelings of tiredness and extreme weariness. Enhanced social support networks increase carers' ability to acquire new skills and take on new responsibilities. Onyeneho and EIlesanmi (2021) argued that the age of the carer might impact the load, particularly when considering the carers' health. Elderly informal carers struggle harder to maintain their well-being due to physical and functional disparities between their health and that of younger individuals. Non-White individuals, those with lower levels of education and income, spouses, those with jobs, those caring for other dependents, and those providing care for longer durations all contribute to the increased strain on informal carers of cancer patients.

Molassiotis and Wang (2022) stated that factors influencing burden can be into four categories: factors related to the caregiver (such as gender, age, and socioeconomic status); factors related to the patient (such as age, health status, and quality of life); factors related to the caregiver-patient dyad (such as the relationship between caregivers and cancer patients); and factors related to caregiving itself (e.g., perceived caregiver burden). Other domains include the connection between the caregiver and the oncologist, organizational assistance, and social norms.

*Intrapersonal Factors:* Another significant variable that affects the results of cancer caregiving is the caregiver's age. Younger caregivers are more prone to experience psychological symptoms than older caregivers, who are more likely to experience bodily health problems. Other key intrapersonal characteristics that could affect the outcomes of cancer caring are the socioeconomic situation of the caregivers, including their level of education, occupation, and income. Self-efficacy was identified by Basil et al (2017) as one of the factors influencing caregiver burden is the assurance of informal caregivers in their capacities to: control behavior and other caregiving stresses; manage troubling thoughts; obtain medical information; manage medical issues; obtain self-care; access community supports; and help with everyday activities;

*Interpersonal Factors:* Relationship between a caregiver and cancer patient is a crucial factor in determining the success of caregiving. Spouses who report more marital satisfaction typically feel better mentally when providing care. However, an uneasy relationship between the patient and the spouse caregiver may hinder them from employing standard dyadic coping, which will lower their quality of life. It's normal for careers and cancer patients to struggle with good communication when it comes to issues with cancer and caregiving. This is a highly significant predictor of depression symptoms in careers both during and following the patient's death.

*Institutional Factors:* One important institutional component that was observed was the health care service schedule. Distress among carers may be exacerbated by the lack of prompt expert assistance in controlling the patient's decline. Unpleasant caregiver feelings might be amplified during clinic visits by long wait periods and an uncomfortable setting. Another crucial institutional aspect that needs to be taken into account is the health care teams' lack of interest in and communication about the welfare of informal caregivers. Many caregivers

believed that health personnel were solely preoccupied with patients and disregarded their worries.

Deenan et al. (2021) that found social support, self-efficacy, gender, duration of care giving and self-efficacy as major factors influencing informal caregivers burden. These factors are both intrapersonal and interpersonal. A carer’s perception of self and the sick relative cared for can influence the wellbeing of both carer and care recipient. Carer becomes easily provoked with the feeling that the patient is overdemanding and he/she lacks support from family and friends. La Johantgen et al. (2021). Conducted a study on Caregiver burden and related factors during end stage cancer and highlighted financial factor such as low income, quality of the relationship between patients and caregivers, having health issues, and lacking family support and self-esteem as linked to higher burden over time. Gemechu et al. (2021) study on Economic Burden of Cancer on Patients relatives revealed significant predictors of caregiver burden as financial factors (=0.154, P=0.010) due to high medical expenses and care recipient dependency factor (=0.154, P=0.010) caused by poor health status, disability, and perceived social support (=0.333, P<0.05). Thana et al. (2021) reviewed 43 papers to ascertain factors contributing to cancer patient caregiver's burden and discovered that physical and mental health of caregivers, their financial situation, their social isolation, their lack of family and social support all played a significant role in the high levels of caregiver burden. The self-esteem of caregivers, male gender, and the dynamic nature of cancer therapy were underappreciated factors that contributed to higher burden. Liua et al. (2020) review analysis on 33 Caregiver burden articles identified three major factors influencing informal care giver burden as multifaceted stress, over time, and one's own perspective. The antecedents included a lack of social activities, a conflict between numerous responsibilities, and insufficient financial resources. Reduced caregiving, a decline in quality of life, and a decline in physical and mental health were some of the bad effects of caregiver burden.

A study on Caregiver burden and associated factors amongst careers of women with advanced breast cancer attending a radiation oncology clinic in Nigeria” by Jite, et al. (2021) revealed that the care recipient's prior hospitalization (p = 0.001) and dysfunction in their activities of daily living (ADL) (OR = 2.57, CI: 1.14 to 5.78) were significantly associated with caregiver burden. More respondents 59 (75%) over the age of 40 reported feeling burdened than their counterparts under that age, with a p > 0.05. Despite the fact that female caregivers looked to be burdened more than male caregivers, gender of the family caregivers was also not significantly associated with burden. The caretakers' education level was significantly correlated with their burden (p = 0.009), with those with less education reporting a heavier burden. There was no statistically significant link between burden and marital status, employment status, or monthly income.

**Perceived Effects of Burden Among Informal Caregivers**

Informal care givers are most times directly affected by patient’s illness as they strive to meet their needs thus neglecting their wellbeing. It is worst if the caregiver has a job and other members of the family to care for with no intermittent time off for someone else to take over care. Informal caregivers break down with physical illness, psychological stress financial difficulty and little or no social life. This severely affects their life quality and accounts for why informal care givers should be captured by health care professional so as to address these needs and make caring for cancer patients less stressful for informal care givers during palliative and end of life. (National Cancer Institute 2021). Some perceived effects of caregiving on informal care givers includes; time constraints, self-development difficulties, low life quality, depressive symptoms, physical health problems (metabolic syndrome, which is characterized by low levels of high-density lipoprotein, high levels of non-fasting glucose, changes in abdominal girth, triglycerides and hypertension), economic issues, anxiety, social isolation, irritability, fatigue/weakness, poor sleep, emotional distress, overreacting to small irritations, developing new or worsening health issues, having trouble focusing, and feeling resentful, intake of drinks, tobacco, or food, leaving most caregiving task undone, limited time for leisure activities, having bouts of common cold, failure to attend to personal needs, does not feel satisfied, feeling of helplessness and hopelessness. However, providing care for cancer patients may also have beneficial effects. such as strengthened caregiver - patient relationship due to mutual support, greater personal growth and caregivers’ adherence to cancer screening due to fear of cancer recurrence in the family (Molassiotis & Wang, 2022; Smith, 2022).

Death is most times considered a natural phenomenon. However, the separation it brings is what contributes to burden among caregivers. Most caregivers express their frustration in seeing their relatives dying without being able to prevent them from dying (Anterrioti et al., 2020). Breen et al. (2019) pointed out that Informal caregivers struggle to see the benefits of caregiving and prepare for the death of the individual they are caring for. About 6%–8% of caretakers are likely to experience complicated grief or prolonged grief and disorder, which is characterized by persistent and pervasive grief distress. It is difficult ascertaining the outcome of caregiving and bereavement on informal care givers. However, it has been identified that high pre-loss grief can be linked with post-loss grief, subjective stress and depression. Anterrioti et al. (2020) grouped perceived effects of informal caregiver burden of people with cancer as physical, psychological, social/behavioral, and financial effects.

*Perceived Physical Effects*: These issues include fatigue, exhaustion, discomfort in various body parts like the head, legs, muscles, shoulders, and neck, a decline in physical stamina, a poor appetite, weight loss or gain, changes in sleeping patterns, a propensity for illness, a hunched posture, and sweaty hands. Sullivan and Miller (2021) opined that most of these physical effects of care burden occur because many caregivers have not had any formal guidance in carrying out physically demanding tasks securely, such as helping with transfers or assisting their care partner with dressing or rising from the floor after a fall. During the most basic caregiving chores, caregivers can easily hurt themselves, but they lack the time to seek medical attention or a replacement caregiver to give them time to recover. People who provide care hardly engage in wellness pursuits, which can be extremely beneficial for both themselves and those they care about.

*Perceived Emotional/Psychological Effects:* Anger, sadness or crying fits, snappishness or irritability, concern or anxiety, discouragement, relaxation difficulty, feeling empty or lost in direction, expecting miracles which are unexplainable, poor concentration, frequent mood swings, adjustment disorder, panic disorder, depression, post-traumatic stress. Sullivan and Miller (2021) added that in situation where the caregiver and the chronically ill family member can jointly handle the illness within the framework of their fuller lives, providing care can be a remarkably emotionally rewarding experience. The caretaker will unavoidably experience challenging and unwelcome negative emotions as the scales begin to tip away from that partnership and toward the caregiver feeling like they are working alone. These unpleasant feelings might pass quickly and be dealt with, particularly if the caregiver is able to mobilize both internal and external resources to come up with effective coping mechanisms. Negative emotions, however, naturally surface as caregivers find themselves in a very real and unavoidable situation with fewer opportunities or methods to regain positive emotional energy.

*Perceived Behavioral Effects:* increased drug or alcohol use, refusal to make decision, poor productivity, forgetfulness, boredom, overreacting, impulsive behavior, and frequent work changes.

*Perceived Financial Effects:* difficulty sustaining source of income, inability to cater for patient’s treatment needs and other family needs. According to Sullivan and Miller (2021) Chronic diseases are extremely expensive to treat; in the United States, caring for people with Chronic diseases costs about $100 billion annually, although these total dollar amounts are enormous, they do not reflect the cost to specific families when the caregiver doubles as the family's main wage earner and frequently takes on low-paying jobs in order to have the flexibility required for caregiving. Due to the fact that such positions do not provide health insurance for the caregiver or other family members, this can further complicate a family's financial situation. The demands brought on by a chronic illness frequently take precedence in a family's budget, which may have an impact on choices regarding a child's college choice, the completion of necessary home repairs, and the sale of family assets. Families with chronic illnesses must budget for every resource in their lives, making these choices are particularly challenging for those families.

*Perceived Social Effects:* Reduced working hours, social isolation, loneliness, reduced leisure time, difficulty staring or maintaining relationships with people, marital issues, intolerance, nagging, poor libido, resentment. Relationships with immediate family and close acquaintances may suffer seriously as energy is devoted to caregiving. Some individuals responsible for their sick relative care laments the demise of their social lives, as they cannot attend several social functions because their care recipient is unable to join them. As the caregiver's duties grow, he or she may continue to fulfill these obligations and may be forced to give up the social aspects of relationships, which can be an important part of them (Sullivan & Miller, 2021).

Ochoa et al. (2021) also stated 4 common health dimensions used to assess perceived effects of burden as physical, psychological, social and spiritual components. They added that greater requests for informal care at the end of life and during palliative care are linked to higher unhealthy physical and emotional state, psychological discomfort, and emotions of life dissatisfaction, which can negatively impact informal care givers overall wellbeing as compared with non-caregivers. Other factors, linked to caregivers’ burden are the number of tasks and duration of time spent providing care for a cancer survivor of which caregivers are not prepared to handle and as such communication, education, and availability of resources to meet needs can get care givers prepared and improve wellbeing. Perceived negative effects of caregiving can be avoided by making a decision to accept the situation, deliberately accepting the function of a caregiver and the advantages of caregiving, looking out for self-wellbeing, focusing on things you have control over etc. (Smith, 2022).

Most studies have identified several perceived effects of care burden among informal care givers. Tülek et al. (2022) Care burden and related factors among informal caregivers revealed that the bulk of the caregivers were female and were either the patients' spouses or children, with a mean age of 48.1 13.4 years. The quality of life was moderate (mean 70.4 22.8). Furthermore, the caregiver's quality of life, social support, anxiety, and sadness were all linked to their burden. A study conducted by Mishra et al. (2021) on Caregiver Burden and Quality of Life among Family Caregivers of Cancer Patients on Chemotherapy showed that seventy-two percent (70.22%) of caregivers reported a mild-to-moderate load, while 21.38 % reported a moderate-to-severe burden. Physical health effect was the smallest, followed by psychological health effects and the highest was negative social relations. The QOL scores were marginally better in mild-to-moderate burden than in moderate-to-severe burden. However, these differences were not statistically significant.

Kolawole et al. (2021) identified that 90.5% of caretakers experienced stress. However, most were moderately impacted by the burden of care (mean=2.86). When caring for a family member with cancer, about 51.1% suffered extreme psychological effects, while 58.1% suffered severe social effects. Age, education level, marital status, and the social demographic characteristics of the respondents were statistically significantly correlated with the burden of care, but there was no statistically significant correlation between gender, occupational position, or the burden of care (p>0.05). A study that looked at how burden can affect the care givers as well as care provided. The research found the life quality of informal caregivers providing care for patients with low function agility were affected while negative impact on care was minimal. This could be due to the support gotten from family and friends. The average impact of caregiver burden was 70.14 points. Negative caregiver burden on the care subscale was lesser (11.80) as compared to positive caregiver worth (13.71) and supportiveness quality was 12.46 (Bartoszek1 et al., 2019)

A systematic review on the effects of burden on caregiver by Ochoa, et al.(2021) revealed high negative effect of burden on psychological distress, physical and mental wellness, social support, and spirituality. Poor quality of life in terms of physical health were observed in informal care givers providing care during acute Phase of the disease. Factors responsible for this poor quality of life includes; low education attainment, having any comorbidities, being female, history of depressive symptoms, caring for a female patient, and assisting patients with poor social well-being scores. Predictability of caregiver routine and working full- or part-time were factors that were favorably associated with higher overall QoL among caregivers. Patient self-efficacy, or perceived ability to manage the illness, was also associated with better physical health among caregivers. Higher levels of mental and social wellbeing were linked to providing care for older patients. Family conflict over switching from active cancer treatment to hospice care was associated with depression, which had an effect on caregivers' functional status and quality of life. Increased effect of burden was reported among people providing care for patients having cancer who lacked family support mostly in the aspect of finance.

**Methods**

A cross-sectional descriptive design using a quantitative method was used. This research was done in Rivers State, Nigeria, at a tertiary hospital. The Hospital is one of the biggest tertiary institutions in Niger Delta. It provides care for several health conditions both on an inpatient and outpatient basis, making it a true representation of the entire population of Port Harcourt. The target population were all informal caregivers of patients with cancer in Port Harcourt. Population for the study were all informal care providers of patients with stage 3 and 4 Cancer attending the hospital either on admission or as out-patient.

The inclusion criteria for participants in the study are informal caregivers providing care for stage 3 and 4 diagnosed cancer patients in the hospital or on an outpatient basis, who have been providing care for at least two weeks, are directly involved in patient care as indicated by the patient, and can understand the English language. Exclusion criteria encompass individuals under 18 years of age, paid, professional, or formal caregivers, as well as eligible participants who are disoriented. A non-probability, convenience sampling was used for the study. This technique allows for easy accessibility of available participants who expressed interest to participate in the study. The Sample size was calculated using Cochran formula by Cochran (1953) which yielded 283 Participants

A validated semi self-structured questionnaire and standardized Instruments (Multidimensional Scale of Perceived Social Support by Zimet et al., 1988 and Revised Scale for Caregiving Self-Efficacy by Steffen et al., 2002) were also adapted to suit the study. The questionnaire comprised of Three (3) sections (A-C).

Section A, was structured to collect socio-demographic data of the respondents.

Section B, was a validated semi self-structured instrument consisting of 26 questions designed to collect data on factors influencing informal care givers burden. The questionnaire was measured on a scale of “Yes or No”. Items 1 to 6 measured social support factors influencing burden among informal care givers, items 7 to 13 measured recipient care dependency factors influencing burden, items 14 to 20 measured financial factors influencing burden while g 21 to 26 measured self-efficacy factors influencing burden among informal care givers. The Multidimensional Scale of Perceived Social Support developed by Zimet et al.(1988) and Revised Scale for Caregiving Self-Efficacy (Steffen, Mckibbin, Zeiss, Gallagher, Bandura, 2002) were partly adapted to suit the objective of this study. For the purpose of this study only 4 major influencing factors such as; social support, dependency, self-efficacy and financial factors was covered.

Section C, was designed to obtain information on perceived effects of burden experienced by informal caregivers for cancer patients during palliative and end of life care. For this study, only 3 domains (physical, psychological and social domains) predominant among several related literatures reviewed were captured. The questionnaire consisted of 18 questions evaluated on a scale of 1 to 4, Agree (A), Strongly Agree (SA), Disagree (D) and Strongly Disagree (SD), Items 1 to 7 measured perceived physical effects of burden, Items 7 to 12 measured perceived psychological effects of burden while item 13 to 18 measured perceived social effects of burden.

The face and content validity was used to validate the study instrument. This was done by reviewing available literatures related to the study objectives and also subjecting the structured instrument to the scrutiny of Test and Evaluation experts for necessary corrections which was effected accordingly to ensure all aspects of the study objectives were completely measured.

The reliability of the instrument was ascertained using test-retest reliability. The researcher administered the questionnaire to 10% of the population size to a group of respondents from another tertiary hospital which had similar characteristics to that of the study area and the test was repeated after 2weeks. Data collected from these respondents were calculated and a correlation coefficient of 0.7 was gotten thus confirming the instrument's reliability.

Following approval of the ethical committee, the researcher employed three research assistants who were educated on the aims of the study, instrument for data collection and how to explain it to the understanding of the respondents. These research assistants then administered the questionnaire to respondents who’s care recipient was on admission in various units of the facility as well as those visiting as out patients in their various clinic days. Approximately 20 minutes was required to fill each questionnaire and data collection process took four weeks. Data was analyzed using SPSS 25.0. Data was analyzed using descriptive statistical techniques such percentages, means, and standard deviation, while multiple regression model was also performed to test for relationships/differences between variables. Results was presented using tables and figure.

 **Objective 1:** To identify factors influencing burden of palliative and end of life care among informal caregivers of people with cancer in a tertiary hospital in Port Harcourt. The questionnaire consisted of 26 items requiring a yes/no response. Data collected was scored (No=1/Yes=2) and analyzed using descriptive statistics (mean, rang and standard deviation). Mean score within the rang (ie between the minimum and maximum score) was accepted as a factor influencing care burden. While a mean score less than the minimum score will be rejected as a factor influencing care burden.

**Objective 2:** To determine Perceived effect of burden of palliative and end of life care among informal caregivers of people with cancer in in a tertiary hospital in Port Harcourt. The questionnaire consisted of 18 items on a 4point scale, Data obtained was analyzed using mean, rang (minimum and maximum score) and standard deviation. A mean score within the rang (between the minimum and maximum score) will be accepted as perceived effect of care burden. While a mean score less than the minimum score will be rejected as a perceived effect of care burden. Furthermore, to determine the domain that was more perceived by caregivers, the level of mean score of each domain was considered.

**Results**

**Socio-Demographics Characteristics Of Respondents**

**Table 1** shows the respondents' socio-demographic characteristics of the respondents. Many (n=176, 63.3%) of the respondents are female. About 101(40%) of the respondents' age group were between 18-28years. Half (n=140, 50.4%) of the respondents were married, had tertiary education (n=140, 50.4%) and were employed (n=101, 36.3%). More than two-fifths (n=120,43.2%) of the respondents are a child of the patient. More than half (n=156, 56.1%) of the respondent’s household sizes were between 1-5 people.

**Table 1: Frequency distribution of respondent’s socio-demographic characteristics**

|  |  |  |
| --- | --- | --- |
| Variables  | **N** | % |
| **SEX:** Female | 176 | 63.3 |
|  Male | 102 | 36.7 |
| **Age (years):** 18-28 | 110 | 39.6 |
|  29-39 | 85 | 30.6 |
|  ≥40 | 83 | 29.9 |
| **Marital status** : Married | 140 | 50.4 |
|  Unmarried | 138 | 49.6 |
| **Level of Education** |  |
| Not educated | 12 | 4.3 |
| Primary | 41 | 14.7 |
| Secondary | 85 | 30.6 |
| Tertiary | 140 | 50.4 |
| **Occupation** |  |
| Employed | 101 | 36.3 |
| Unemployed | 34 | 12.2 |
| Trader | 57 | 20.5 |
| Farming | 30 | 10.8 |
| Others | 56 | 20.1 |
| **Relationship to patient**  |
| Spouse | 49 | 17.6 |
| Child | 120 | 43.2 |
| Distant relative | 92 | 33.1 |
| Friends | 17 | 6.1 |
| **Household size** |  |
| 1-5 | 156 | 56.1 |
| 6-10 | 101 | 36.3 |
| ≥11 | 21 | 7.6 |

**Objective 1: Factors influencing caregiving burden among respondent**

Table 2shows factors influencing care burden among respondents**.** Financial Factor was the highest (Mean 8.83±2.21, rang 5.00), followed byCare Recipient Dependency Factor (Mean 8.61, std 1.46, rang 7), Social Support Factor (mean/std 6.93±1.23, rang 5.00) while Self-Efficacy had a mean that is not between the minimum and maximum rang self-efficacy (mean/std 4.7±1.04, rang 3)

|  |
| --- |
| **Table 2: Descriptive Statistics of Factors influencing caregiving burden among respondents Descriptive Statistics** |
|  | N | Range | Minimum | Maximum | Mean/Std |  |
| Social Support Factor | 278 | 5.00 | 6.00 | 11.00 | 6.93±1.23 |
| Care Recipient Dependency Factor | 278 | 7.00 | 6.00 | 13.00 | 8.61±1.46 |  |
| Self-Efficacy Factor | 278 | 3.00 | 5.00 | 8.00 | 4.07±1.04  |
| Financial Factor | 278 | 9.00 | 5.00 | 14.00 | 8.83±2.21 |  |
| Valid N (list wise) | 278 |  |  |  |  |

**Objective 2: Respondents’ Perceived Effect of Caregiving Burdens**

Table 3 shows that Perceived psychological effect of burden had a mean±std of 13.20±4.0 and a range of 16.00. Perceived physical effect mean±std score was 11.71±3.3 and the range was 15.00 and Perceived social effect had a mean±std of 9.90±3.0 and a range of 10.00. Furthermore, respondents perceived psychological, physical effect and social effect care burden but at varying degree. The overall mean±std and range score for respondents’ perceived effect of care burden were 34.8±6.8 and 32.00 respectively

**Table 3: Descriptive Statistics of Respondents’ Perceived effect of caregiving burdens**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Variables | N | Range | Minimum | Maximum | Mean±SD |
| Perceived Physical Effect | 278 | 15.00 | 4.00 | 19.00 | 11.71±3.3 |
| Perceived Psychological Effect | 278 | 16.00 | 6.00 | 22.00 | 13.20±4.0 |
| Perceived Social Effect | 278 | 10.00 | 6.00 | 16.00 | 9.90±3.0 |
| Overall Perceived Effect | 278 | 32.00 | 18.00 | 50.00 | 34.81±6.8 |
| Valid N (list wise) | 278 |  |  |  |  |

**Discussion of Findings**

The finding of this study showed that Financial Factor (Mean 8.83), Care Recipient Dependency Factor (Mean 8.61), and social factor (6.93) were major factors influencing care burden among respondents. Self-efficacy factor was underappreciated as a factor influencing burden. This finding is similar to that of Gemechu et al. (2021), La Johantgen et al. (2021) and La Johantgen et al. (2021) who identified Financial Factor, Care Recipient Dependency Factor, and social factors as factors influencing care burden among respondents. Care providers who are the only ones taking care of their sick relatives and those who are not furnished with adequate information tends to experience social isolation. On the other hand, ICG who help care recipients with feeding, bathing, dressing, shopping, getting in and out of chairs over long period leads to burden. Furthermore, combining a job with caring for a sick relative reduces work hours which in turn cuts down financial income. High cost of medical treatment.

The result of this study established that perceived psychological effect (Mean±SD 13.2±4.0/rang 16.00) of burden was the highest, followed by perceived physical effect (Mean±SD 11.7±3.3/range 15.00) and the least perceived was social effect. (Mean±SD 9.9±3.0/range of 10.00). This finding implies that ICG perceived more of psychological and physical effects of burden as affecting their wellbeing as compared to social effects. The finding of Liua et al. (2020) and Ochoa et al. (2021) corresponds to the finding of this study as they noted a higher decline in mental and physical health as bad effects of care burden among unpaid caregivers compared to social health. Contrary to the finding of this study was the study of Kolawole et al. (2021) who documented severe social effect of burden among respondent as compared to psychological and physical effects of burden. This may be due to lack of social support from friends and family. The findings of Kocak, et al. (2022) was also different from the finding of this study. They stated that physical effect of burden affected the wellbeing of respondent more than psychological and social effects. Reason for this difference in finding may be as a result the difference in hours spent in giving care, duration of care provided and the level of dependency of the care recipient.

**Conclusion**

The study's findings highlight the significant impact of financial factors, care recipient dependency, and social support on caregiving burden, with self-efficacy being comparatively less recognized. Caregivers providing extensive care for their sick relatives may experience social isolation, compounded by the challenge of balancing caregiving responsibilities with employment, leading to reduced income. The high cost of medical treatment further exacerbates financial strain. Regarding perceived effects of caregiving burdens, caregivers reported the highest psychological impact, followed by physical effects, with social effects being perceived to a lesser extent. These findings suggest that caregivers may experience greater mental and physical strain compared to social challenges. While previous research has documented similar trends, some variations exist, possibly due to differences in caregiving hours, duration, and care recipient dependency levels.

**Recommendations**

Based on findings of the study, the following recommendations were proposed.

* Health education and follow up of informal care providers of patients’ during active treatment of cancer and towards death by health professionals.
* Nurses should encourage members of care recipient family through advocacy to ensure rotational care giving among relatives to reduce stress on one care giver.
* Prompt assessment of unpaid care provider of patients with advance cancer by health care professionals for burden and its effects.

**COMPETING INTERESTS DISCLAIMER:**

Authors have declared that they have no known competing financial interests OR non-financial interests OR personal relationships that could have appeared to influence the work reported in this paper.

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