

Psychological Buffers of the Burden of Caregiving among Caregivers of Cancer Patients in University College Hospital, Ibadan, Nigeria

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Abstract

A review of informal caregivers' needs within palliative care has shown that there seems to be a distinct risk of psychological distress for family caregivers during their caregiving role. This study, therefore, provides insight into caregiving burden and potential buffers among relatives of cancer patients in the University College Hospital (UCH) Ibadan. The study adopted a cross-sectional descriptive survey design, in which total enumeration via purposive sampling technique was utilised in obtaining 80 caregivers for the study. A structured questionnaire was utilised in eliciting relevant information relating to the participants of the study. Hypotheses were formulated in line with the study objectives and tested using appropriate statistics at 0.05 level of significance. All of the cancer patient caregivers in this study reported high levels (82.5%) to severe levels (17.5%) of caregiving burden. Social support from friends ($\beta = -.355$; $p < .05$) and emotion-based coping ($\beta = -.315$; $p < .05$) emerged as significant negative predictors of caregiving burden among caregivers of cancer patients in UCH. There was no significant difference in the caregiving burden between male and female caregiving relatives of cancer patient in UCH [$t(78) = .547$; $p > .05$]. There was a significant influence of age on levels of caregiving burden among relatives of cancer patients in University College Hospital [$F_{(3,76)} = 2.367$; $p < .05$] with results suggesting that younger caregivers of cancer patients reported higher caregiving burden than their older counterparts. To that end, the study recommends a transformation in the policies and practices affecting the role of families in the support and care of terminally ill patients.

Introduction

Cancer and cancer treatment affects not only the patients but also their family members and caregivers. When giving care to persons with life-threatening illnesses such as cancer, caregivers are confronted with physical and emotional challenges (Blindheim, Thorsnes, Brataas & Dahl, 2013). Some studies report that the impact of a cancer diagnosis is greater on family members than it is on patients (Girgis, Lambert, Johnson, Waller & Currow, 2013). During the course of illness when cancer patients are not admitted to the hospital, family caregivers assume significant roles to support the patients. However, caregiving does not cease during hospitalisation (Girgis *et al.*, 2013). Caregiving becomes a full-time job once the patient needs assistance with even the most basic activities of daily living due to the effects of the disease, the treatments, or the combination of cancer and comorbidities. Providing care to cancer patients is demanding. Caring roles and responsibilities start when cancer is diagnosed. The complexity and uniqueness of the care given to cancer patients varies depending on the type of cancer, stage of the illness, and type of cancer treatment. Care giving continues and can extend for several years until the cancer is cured or takes the life of the afflicted person. Supportive activities include household tasks, emotional support, and managing money. Cancer patient care has both positive and negative

impacts on the caregivers. Many caregivers experience a high level of satisfaction from their caring roles; conversely, many report a significant burden to their physical and psychological well-being, economic circumstances, and social and personal relationships (McPherson, Hadjistavropoulos, Lobchuk & Kilgour, 2013).

Caregiver burden is the reaction to stressors that accumulate from caregiving duties, time restrictions, and difficulties in providing care (Ampalam, Gunturu & Padma, 2012). A caregiver is an unpaid individual who provides direct care to relatives or friends who are unable to provide for themselves while burden is an “oppressive or worrisome load” (Obaidi & Al-Atiyyat, 2013). Therefore, caregiver burden can be described as the worrisome load borne by people providing care for another individual. The concept has also been defined as the physical, psychological or emotional, social, and financial problems experienced by caregivers resulting from changes in cognition and behaviour of the patient and the patient’s subsequent need for care and supervision (Stenberg, Ekstedt, Olsson & Ruland, 2014). Caregivers provide long-term care and are often the primary source of physical, social, and emotional support for patients. Depending on the responsibility assigned, caregivers have been classified as primary caregivers if they are mainly responsible for providing and/or assisting with the care recipients’ activities of daily living or secondary caregivers if they assist in caregiving or provide support to a care recipient but are not primarily responsible for the day-to-day care or decisions regarding that care. It is important to note that secondary caregivers are critical to the network of support for primary caregivers. In the past three decades, studies have documented negative caregiver outcomes in the context of the stress response that arise from the introduction of new care demands or escalation of existing demands (Sherwood, Given, Given & von Eye, 2005).

A patient’s disease affects family members. There may be increased costs for the family members, but also reduced quality of life. The risk of poor health outcomes has to be identified in order to better support struggling caregivers (Ampalam, Gunturu & Padma, 2017). The role of caregiver can involve a restriction on activities and leisure-time, which can negatively affect the caregivers’ mental health. Informal caregiving may also have some influence on work attendance and productivity, creating an economic burden for the family (Dionne-Odom *et al.*, 2016). Health-service professionals are considered when a family cannot provide informal care. Instruments in earlier research have usually been developed for measuring costs in connection with a patient’s particular treatment or for a shorter period than one year. Increased caregiving obligations often result in a loss of free time, friendships, and social isolation (Rodriguez *et al.*, 2003). The transition from family member or friend to one who provides care for a loved one with cancer is sudden and unplanned. There is little time for preparation or for the caregiver to learn how to perform the various tasks that will be required throughout the care situation. This transition may have a large impact on the caregiver’s life as they take on new roles and responsibilities. The literature over the past several decades has shown that providing care to a loved one with cancer or dementia may cause negative emotional and physical responses in the caregiver (Pinquart & Sorenson, 2003).

There is a need to help caregivers by providing them with better information about their new life situation and about how to buffer the burden of illness (Francis, Worthington, Kyriotakis & Rose, 2010). One of such buffers may be an effective application of coping strategies to mitigate caregiving burden. Persons providing informal caregiving for cancer patients have a tendency to use both problem-focused and emotion-focused coping strategies in respect of the most traumatic events (Kent *et al.*, 2016). Problem-focused coping implies grappling with the problem by acting

or seeking information. Emotion-focused coping implies regulating one's distress by avoiding feelings or situations reminding one of the sources of this distress, and it can also be a question of seeking support. Coping strategies have been of great help to caregivers in the case of patients with cancer, though in fact there has been little research on family caregivers' coping strategies. During the caregiving process, worrying and expecting the worst, have negative psychological outcomes on the mental health of persons providing informal caregiving for cancer patients.

The person's management of the resultant distress partially depends on the support he or she receives from the family and the social network, and social support is regarded as a resource for management of stress (Leone & Leone, 2015). One approach to defining social support is to make a distinction between structural and functional support. Structural support implies a network of interpersonal relationships involving relatives, friends and co-workers through which the person is attached to a community. Functional support is described in terms of the provision of information, tangible support and emotional support. A support network can be a resource for family members in a time of crisis. The achievement of better health includes the interaction of people who give each other emotional support, informative material and practical support. These aim at giving people the possibility of control over the factors that influence health and decreasing the negative factors that cause social strain. Social support can be described as a resource that other people constitute for a specific person. It involves the mutual exchange of information that is characterised by advocacy and described with affect, affirmation and aid. It can also be described in terms of being in contact with people one has trust in or people who care and who value one as a person.

A systematic review of informal caregivers' needs within palliative care has shown that there is a lack of practical guidance and that caregivers often receive less practical professional support and information than they need. Caregivers are mostly alone in providing support for the cancer patient in the patient's home. The period immediately following the diagnosis is usually characterised by doubts about the future and an effort to be prepared for negative outcomes. There seems to be a distinct risk of psychological distress for the family members overall; such that there is an increasing need for caregivers to be better helped with special support programmes for the role of informal provider of care, as well as with regard to their health. This study, therefore, tries to provide insight into the psychological buffers of caregiving burden among caregivers of cancer patients.

Empirical Review: Caregiving Buffers

Johansen, Cvancarova and Ruland (2018) examined the effect of cancer patients' and family caregivers' symptoms and demographic characteristics on caregiver burden at the initiation of the patients' radiation treatment. Two hundred eighty-one dyads of family caregivers and cancer patients who received a diagnosis of breast, prostate, melanoma, lymphoma, and head and neck cancers were recruited at the beginning of the patients' radiation treatment. There were significant associations between caregiver burden and the *patient-related* variables such as self-efficacy, sleep disturbance, and social support. Among family caregiver-*related* variables, higher scores of depression, fatigue and symptoms were significantly associated with higher caregiver burden. Being a female, either as a patient or family caregiver, increased the likelihood of experiencing fatigue and sleep disturbance.

Akpan-Idiok and Anarado (2014) studied the informal caregivers' perceptions of burden of caregiving to cancer patients attending University of Calabar Teaching Hospital, Calabar. The research adopted a cross-section descriptive design and 210 caregivers providing care to advanced cancer patients were purposively selected. Data were collected using a researcher developed questionnaire and standardised Zarit Burden Interview scale (ZBIS). Results indicated that psychological and social forms of burden had the highest weighted score of 228 in terms of the magnitude of burden. The result further showed that there was a significant and inverse association between caregivers' burden and the care receivers' functional ability. The level of burden also increased significantly with the duration of care, while there was also a significant relationship between caregivers' experience of burden and their desire to continue caregiving.

Ge and Mordiffi (2017) identified factors associated with high caregiver burden among family caregivers of elderly cancer patients. A systematic search of 7 electronic databases was conducted in which best-evidence synthesis model was used for data synthesis. The search yielded a total of 3339 studies and 7 studies involving 1233 family caregivers were included after screening and full assessment of 116 studies. Moderate evidence supported that younger caregivers, solid tumours, and assistance with patient's activities of daily living were significantly associated with high caregiver burden. Eighteen factors were supported by limited evidence and one factor was a conflicting factor. The evidence indicated that family caregivers who were at a younger age, caring for solid tumour patients, and providing assistance with patient's activities of daily living reported high caregiver burden.

Borges, Franceschini, Costa, Fernandes, Jamnik and Santoro (2017) evaluated the impact that lung cancer stage and quality of life (QoL) of lung cancer patients have on caregiver burden. Family caregivers completed the Caregiver Burden Scale. Patient-caregiver dyads were stratified into four groups: early-stage cancer+non-impaired QoL; advanced-stage cancer+non-impaired QoL; early-stage cancer+impaired QoL and advanced-stage cancer+impaired QoL. The majority of the patients were male and heavy smokers. Family caregivers were younger and predominantly female. The burden, QoL, level of anxiety, and level of depression of caregivers were more affected by the QoL of the patients than by their lung cancer stage. The family caregivers of patients with impaired QoL showed a higher median burden than did those of the patients with non-impaired QoL, regardless of disease stage.

Mirsoleymani, Rohani, Matbouei, Nasiri and Vasli (2017) examined caregiver burden and family distress and the relationship between them. They also tried to explore predictors of caregiver burden in a sample of Iranian family caregivers of cancer patients. This was a cross-sectional study with correlational design. A total of 104 family caregivers of cancer patients were asked to respond to the Caregiver Burden Inventory (CBI) and the Family Distress Index (FDI) together with a sociodemographic questionnaire. A high burden was experienced by almost half of the caregivers (48.1%). The FDI mean score was 9.76 ± 5.40 ranged from 0 to 24. A strong positive correlation was found between the caregiver burden and family distress. Multiple linear regression results showed the predictive role of FDI score, patient's gender, and early cancer diagnosis in caregiver burden.

Oyegbile and Brysiewicz (2017) explored the caregiver burden of family caregivers of End-Stage Renal Disease (ESRD) patients in South-West Nigeria. Following a complementary mixed method data collection strategy, the quantitative data was collected using the Zarit Burden

Interview questionnaire to measure the burden of caregiving. Qualitative data was thereafter obtained through in-depth, individual interviews and was analysed using content analysis. The three research settings consisted of two state hospitals and one private hospital that provide renal care in South-West Nigeria. The mean burden of caregiving for the sample was 50.18 thus indicating that family caregivers experienced moderate to severe burden, which is high compared to the other studies. The participants' experiences of caregiving revealed the following categories: total dependence, acceptance of caregiving role, competing responsibilities, financial sacrifice and "not making mistakes".

Asuquo, Etowa and Adejumo (2013) examined the level of burden and the extent of support on family caregivers of people living with AIDS (PLWHA) in Calabar, South East Nigeria. A mixed method with a cross-sectional approach was used. Purposive sampling technique guided the recruitment process and data collection methods included semi-structured questionnaires and focusing group discussion. The 260 respondents participated in the study. Results indicated a high level of burden with limited support to caregivers. A Chi-square value of 25.1 was obtained at $P < 0.05$, suggesting a significant relationship between the availability of support and caregivers burden. This relationship was supported by the themes of physical, social, emotional and financial burden for the caregivers. Similarly, information on coping skills, emotional support, financial assistance and help with caregiving themes emerged for social support.

Ustaalioglu, Acar and Caliskan (2018) identified the predictive factors for the perceived family social support among cancer patients and caregiver burden of their family caregivers. Participants were 302 and this consisted of cancer patients and their family caregivers. Family social support scale was used for cancer patients and burden interview was used for family caregivers. All subjects also completed Beck depression inventory. Depression scores were higher among patients than their family caregivers. PSS was lower in depressed patients. Family caregiver burden was also higher in depressive groups. Among patients, only the depression was negatively correlated with PSS. Presence of depression was positively correlated and family caregiver role was negatively correlated with caregiver burden. Presence of depression was the independent predictor for both, lower PSS for patients and higher burden for caregivers.

Hypotheses

Based on the logical and empirical trends from related literature, the following research hypotheses are formulated for testing.

- H₁: There will be significant influence of social support and coping on caregiving burden among relatives of cancer patients in University College Hospital.
- H₂: There would be significant gender difference in caregiving burden among relatives of cancer patients in University College Hospital
- H₃: Age of caregivers would significantly influence caregiving burden among relatives of cancer patients in University College Hospital.

Methods

Research Design

The study adopted a cross-sectional descriptive survey design and was conducted within the wards of the oncology clinic and the hospice and palliative care unit in the University College

Hospital (UCH) Ibadan, Oyo State. These wards provide treatment services that relieve pain and suffering and as well provide support for patients and their families throughout the course of chronic and ultimately fatal illness such as cancer. The target population for this study included relatives and friends who are providing additional caregiving services for cancer patients in the hospital wards. This included both male and female caregivers across all ages.

Sample Size and Sampling Technique

Due to the limits of the eligibility criteria, total enumeration using purposive sampling technique was adopted. This involved making a conscious effort to reach out to any family caregiver for cancer patients who was available during the course of the data collection period. The participants were approached during their regular visits to provide caregiving services to their loved ones. Consents of participants were however obtained.

Participants

A total of 80 participants were eventually obtained for the study. Frequency distribution of the participants showed that 3.8% of the respondents were within ages 30-39 years, 35% of the respondents were within ages 40-49 years, 48.8% of the respondents were within ages 50-59 years while 12.5% of the respondents were within ages 60-69 years. In terms of their gender, 48.8% were male while the remaining 51.2% were female. Marital statuses showed that 6.3% of the caregivers were single, 90.0% of them were married while 3.0% were widowed. As regards their educational statuses, more than half (52.5%) of the respondents were first degree holders, while 21.3% were master degree holders. The others included O'level (7.5%), OND (5.0%) and HND (13.8%) holders. Finally, 70.0% of the respondents were Yoruba, 16.3% were Igbo while 13.8% were Hausa.

Measures

A structured questionnaire was utilised in eliciting relevant information relating to the participants of the study. The questionnaire was made up of standardised scales that measure the study variables. Section A consisted of items that describe the demographic characteristics of the participants of the study such as age, sex, marital status, educational status, religious affiliation, ethnicity etc.

Section B comprised items from the Zarit Caregiver Burden Interview. The scale has 21 items which evaluate the perceived impact of providing care to physical and emotional health, social activities and financial condition. Responses to the 21 items are provided on a five-point scale that describes how each statement affects the person. The total score is obtained by adding up all items and ranges from 0 to 88. The original author reported a Cronbach alpha of .82 for the scale.

Section C contained items from the *Multidimensional Scale of Perceived Social Support* (Zimet, Dahlem, Zimet & Farley, 1988). The MSPSS is a 12-item scale designed to measure perceived social support from three sources: Family, Friends, and a Significant Other. Each of these forms a separate subscale; however, a composite score of overall social support can also be obtained. It is rated on a 5-point scale ranging from '1 = Strongly Disagree' to '5 = Strongly Agree'. Previous studies (Bada, Balogun & Adejuwon, 2014) on a sample of the middle-aged working-class adult Nigerian population, have established the internal consistency (Cronbach's alpha) of MSPSS at 0.92.

Section D was made up of items from the Brief COPE (Carver, 1997). The Brief COPE (Carver, 1997) is a self-report questionnaire used to assess a number of different coping behaviours and thoughts a person may have in response to a specific situation. It is made up of 14 subscales: self-distraction, active coping, denial, substance use, use of emotional support, use of instrumental support, behavioural disengagement, venting, positive reframing, planning, humour, acceptance, religion, and self-blame. After reading a situationally-specific scenario, 28 coping behaviours and thoughts (2 items for each subscale) are rated on the frequency of use by the the participant with a scale of 1 (—I haven't been doing this at all) to 4 (—I've been doing this a lot). Internal reliabilities for the 14 subscales range from $\alpha = 0.57-0.90$ (Carver, 1997).

Validation of Instrument

In order to measure the extent to which the survey instrument was able to achieve their aims, the process of content validity was employed by cross-examination and verification. The knowledge gained from other investigations, literature review, theoretical framework and research methods was used as face validation for the contents of the instrument. In addition, a more practical avenue of validity included consultation within and outside the department of the researcher. This provided the opportunity to check and test the items as the work progressed. In addition, the researcher extended the frontier of consultation to the project supervisor for necessary critic and suggestions for amendment on the draft of the research instrument. Cultural relevance of items was considered and some items were reworded if necessary.

Procedure

The administration of the research instruments for this study was accomplished by the following procedure. Upon completion of the administrative arrangements with the appropriate management, the researchers made regular visits to the wards, where contact was made with family caregivers of cancer patients. These contacts entailed a one-on-one session with the participants and included an introduction to the study. Instructions (both verbal and printed) for completing the instruments and the actual completion of the instruments were explained. Respondents were encouraged to ask clarification questions during the giving of instructions and completion of the instruments. In cases where respondents preferred to complete the instruments later, during their own convenience, arrangements were made for collection of such completed instruments during subsequent visits. Only participants who gave their consent to participate in the study were selected. Participants who were unable to complete the instruments due to difficulties in hearing, sight or understanding were exempted from the study. Only completed questionnaires were used in the data analyses. Following the completion of the data collection, the copies of the questionnaire were coded, scored and input in an SPSS program for analysis. Both descriptive and inferential statistics were employed in the data analysis of the study.

Ethical consideration

All the necessary research ethical standards were strictly adhered to during the data collection process; these include

Confidentiality: Responses of participants in the study were treated as confidential. Names, addresses and other forms of identification were used during the study. All data obtained in the course of the study were used strictly for academic research purposes.

Use of Acceptable Vocabulary: Questionnaire items were presented using comprehensive and socially acceptable vocabulary.

Benevolence to Participants: The outcomes of the study would be of benefit to the participants as well as other members of the population involved. This will be achieved by ensuring that a good measure of feedback is carried out through publication of results and recommendations for public consumption.

Non Malevolence to Participants: The procedure for data collection included non-invasive methods which posed no physical threat to the life and safety of the participants.

Voluntariness: Only potential participants who consented to participate in the study were included. Furthermore, their right to opt-out at any stage of the study was upheld.

Informed Consent: Verbal permission to participate in the study was obtained from the participants before questionnaire administration.

Results

Prevalence of caregiving burden

The prevalence of caregiving burden among the respondents was sought based on the ratings of the Zarit Burden Interview.

Table 1: Prevalence of Caregiving Burden

			Frequency	Percent
Caregiving Burden	No Burden	0 - 21 little or no burden	0	0.0
	Mild Burden	21 - 40 mild burden	0	0.0
	High Burden	41 - 60 high burden	66	82.5
	Severe Burden	61 - 84 severe burden	14	17.5
Total			80	100.0

Results from Table 1 show that no respondent reported little or mild burden of caregiving. However, 82.5% of them reported high caregiving burden while the remaining 17.5% reported severe caregiving burden. The results from Table 1 imply that majority of cancer patient caregivers experience high to severe burden while caring for their sick family members or relatives.

Hypotheses Testing

Three hypotheses were formulated in line with the study objectives and tested using appropriate statistics. Results are presented in the following sections.

Hypothesis One

There will be significant influence of social support and coping on caregiving burden among relatives of cancer patients in University College Hospital. This hypothesis was tested using multiple regression analysis. Results are presented in Table 2

Table 2: Summary of Multiple regression showing influence of social support and emotion-based coping on caregiving burden

	R²	F	Sig	β	t	Sig.
Social Support (Special Person)				.065	.602	.549
Social Support (Family)				-.167	-1.530	.130
Social Support (Friend)	.192	3.520	.007	-.355	-2.969	.004
Problem Focused Coping				-.143	-1.000	.321
Emotion Based Coping				-.315	-2.334	.022

Results from Table 2 show that social support and coping jointly predicted caregiving burden among caregivers of cancer patients in the University College Hospital (UCH) [$F_{(5,74)}=3.520$; $p<.05$] and accounted for 19.2% of the variance in the levels of caregiving burden. However, social support from friend ($\beta=-.355$; $p<.05$) and emotion-based coping ($\beta= -.315$; $p<.05$) emerged as significant independent negative predictors of caregiving burden among caregivers of cancer patients in UCH. The results imply that having less support from friends increasing the experience of caregiving burden (and vice versa), while employing emotion-based coping decreases the level of caregiving burden. The hypothesis stated is therefore supported.

Hypothesis Two

There will be significant gender difference in caregiving burden among relatives of cancer patients in University College Hospital. This hypothesis was tested using t-test for independent measures. Results are presented in Table 3.

Table 3: t-test summary showing influence of sex on caregiving burden

	Sex	N	Mean	Std. Dev.	df	t	sig
Caregiving Burden	Male	39	47.05	3.4023	78	.547	.586
	Female	41	46.53	4.8481			

Results from Table 3 show that there was no significant difference in caregiving burden between male and female caregiving relatives of cancer patient in UCH [$t(78)=.547$; $p05$]. The results imply that both male and female caregivers of cancer patients reported a similar level of caregiving burden. In other words, sex did not influence the level of caregiving burden experienced by caregivers of cancer patients. The hypothesis stated is therefore rejected.

Hypothesis three

Age of caregivers will significantly influence caregiving burden among relatives of cancer patients in University College Hospital. This hypothesis was tested using one-way ANOVA. Results are presented in Table 4

Table 4a: Influence of Age on Caregiving Burden

	Sum of Squares	Df	Mean Square	F	Sig.
Between Groups	118.396	3	39.465	2.367	.047
Within Groups	1266.991	76	16.671		
Total	1385.387	79			

Results from Table 4a show that there is a significant influence of age on levels of caregiving burden among relatives of cancer patients in University College Hospital [$F_{(3,76)}=2.367$; $p<.05$]. The results imply that there is a significant variance in caregiving burden experienced across the four age groups within the study. A post hoc analysis was therefore conducted to rank the caregiving burden experienced by the different age groups. Results are presented in Table 4b.

Table 4b: Multiple comparison and mean rank of caregiving burden among relatives of cancer patients in University College Hospital

	1	2	3	4	Mean	Std. Dev	Rank
1. 30-39 years		.083	2.69*	1.63	48.3333	1.15470	1 st
2. 40-49 years			2.61*	1.55	48.2500	5.09629	2 nd
3. 50-59 years				-1.06	45.6410	3.56509	4 th
4. 60-69 years					46.7000	2.98329	3 rd
Total					46.7875	4.18767	.

* The mean difference is significant at the 0.05 level.

Results from Table 4b show that caregiver of ages 30-39 years experienced the highest levels of caregiving burden ($\bar{x}=48.333$) for cancer patients, while caregiver of ages 50-59 years experienced the least levels of caregiving burden ($\bar{x}=45.641$). The results, therefore, suggest that younger caregivers of cancer patients reported higher caregiving burden than their older counterparts. Furthermore, LSD results on caregiving burden showed that mean differences that were greater than (or equal to) ± 2.61 were significant at $p<.05$. The hypothesis stated was therefore supported.

Conclusion

Discussion of Findings

The study aimed at assessing perceived psychological effects of caregiving burden among relatives of cancer patients in UCH. Results showed that 82.5% of the caregivers reported high levels of caregiving burden while the remaining 17.5% reported severe levels of caregiving burden. This suggests that all of the cancer patient caregivers in this study experienced high to severe burden while caring for their sick family members or relatives. In justifying the results obtained in this study, the health of a person with cancer may also affect caregivers' risk of ill health, though studies have reported mixed results on this subject (Christakis & Allison, 2006; Fredman, Cauley, Hochberg, Ensrud & Doros, 2010). For instance, in the study done by Christakis and Allison (2006), it was reported that higher levels of stress and depression were associated with higher rates of mortality in family caregivers for person with cancer. These findings suggest that high pressure in caregiving role is the leading cause that increases risk of

illness and mortality among family caregivers (Fredman *et al.*, 2010). The pressure of cancer caregiving is influenced by a number of other factors, such as disease severity, caregiver's ability to accept the challenge of caregiving, available social support and caregiver personality. All of these aspects are essential to note to comprehend the health impact of caregiving for a person with cancer.

Based on this study's outcome, family caregivers for persons with cancer may experience poor quality of life. Numerous studies have found that emotional distress and psychological well-being remain relatively constant for dementia caregivers after institutionalisation (Lieberman & Fisher, 2001). Moreover, institutionalisation brings new responsibilities and roles for the family caregivers, and sometimes, negative interactions between family caregivers and institution staff trigger negative impacts on family caregivers' stress and well-being (Gaugler *et al.*, 2004). Demands of caregiving may get intense and challenging for caregivers when care recipients approach the end of life. In one of the studies done by Schulz and associates (2004), it was found that in the year before the person's death, 59 percent of caregivers felt they were "on duty" 24 hours a day, and many felt that caregiving during this time was extremely stressful. The same study also found that 72 percent of family caregivers said they experienced relief when the person with cancer died.

The physical health of caregivers during cancer caregiving also deteriorates over time. Often caregivers perceive that demands of caregiving may cause a decline in their own health. People with cancer may experience a greater risk of chronic disease, physiological impairments, increased health care utilisation and mortality than those who are non-caregivers (Vitaliano, Zhang, & Scanlan, 2003). Sleep disturbances, which can occur often while taking care of a relative with cancer have also been said to negatively influence family caregivers' health (Yusuf, Adamu & Nuhu, 2010). The chronic stress of caregiving is associated with physiological changes that indicate the risk of developing chronic conditions. Recent studies found that under certain conditions some cancer caregivers are more likely to have prominent biomarkers of cardiovascular disease risk and impaired kidney function risk than those who are not caregivers (Vitaliano *et al.*, 2003).

Results from the analysis of hypothesis one, which stated that there will be significant influence of social support and coping on caregiving burden among relatives of cancer patients in University College Hospital showed that social support from friends and emotion-based coping emerged as significant negative predictors of caregiving burden among caregivers of cancer patients in UCH. The results imply that having less support from friends increasing the experience of caregiving burden (and vice versa), while employing emotion-based coping decreases the level of caregiving burden. These results may be justified based on the fact that friends are often more accessible (since friends can be anybody around us bonded by some emotional interaction) than family members (who are limited to blood ties) in times of need. Furthermore, emotional support is more readily available from friends than family members, since friendship is often a product of emotional attachment, and no obligations. This may, therefore, account for the buffering nature of emotion based coping methods on caregiving burden among cancer caregivers.

Moreover, in caregiving, social support has been analysed under the stress and coping models derived from the Transactional Stress Theory by Lazarus and Folkman (1984). In these models, the consequences of the potential stressful events depend on the caregiver's personal appraisal of

these events and the caregiver's resources such as social support. Based on these models, some authors have tried to theorise how social support modulates the stress consequences. In this sense, it is argued that social support may play a role at two different points in the causal sequence, linking stress to its consequences. First, the perception that others can provide necessary resources could lead to appraising a situation as less stressful. Second, the actual receipt of support may alleviate the impact of stress by providing a solution to the problem, by reducing the perceived importance of the problem, by providing distraction from the problem or by facilitating healthful behaviours. Thus, social support could diminish the impact of stressors on caregiver's emotional situation.

Corroborating the results obtained in this study, del-Pino-Casado *et al.* (2018) found a moderate, negative association of perceived social support on subjective burden of cancer care. Despite the generally accepted belief that social support improves caregiver adjustment in general and subjective burden, in particular, the literature shows mixed findings, existing works have linked social support to less subjective burden (Smerglia *et al.*, 2007), more subjective burden (Kruithof *et al.*, 2016) or shown no relationship (Melrose, Brown & Wood, 2015). Moreover, a recent review about social functioning (including social support) and subjective burden in caregivers (del-Pino-Casado *et al.*, 2018) concluded that the predictive strength of caregiver social support in determining caregiver burden is less evident, due to the conceptual diversity of this determinant. Researchers have tried to explain previous heterogeneity and scarcity of evidence by analysing perceived and received social support separately, based on the hypothesis that perceived support has more consistently related to beneficial health outcomes than received social support (Annisa, 2015).

The second hypothesis which stated that there will be significant gender difference in caregiving burden among relatives of cancer patients in University College Hospital was rejected. The outcomes showed that both male and female caregivers of cancer patients reported a similar level of caregiving burden. In other words, sex did not influence the level of caregiving burden experienced by caregivers of cancer patients. In justifying the results obtained in this study, the act of cancer caregiving does not often require gender dexterities. Caregiving activities are often determined by the specific needs of the patient which may or may not be gender sensitive. Moreover, it may be the dynamics of same sex or opposite sex caregivers which may play a role in the variance of caregiving burden experienced by caregivers.

Contrary to the findings, literature posits that gender differences should exist in perception and coping levels of caregivers. The limited literature on sex and gender influences on caregiving burden has found differences in well-being, psychosocial and overall health status between male and female caregivers through cross-sectional surveys (Prince *et al.*, 2016). Additionally, differences were also observed in relation to subjective measures of health and well-being, with female caregivers reporting a greater perception of ill health and lower levels of quality of life than male caregivers (O'Rourke *et al.*, 2010). Similarly, the forms of caregiver burden and stress experienced were also heavily influenced by sex distinctions. While male caregivers were found to experience low morale and a greater need for social support, the burden experienced by female caregivers was often attributed to their relationships with other family members (Hartling, Featherstone & Nuspl, 2017).

Gender-differences in the time spent on caregiving have been considered in several reviews and studies on the subject. Some of them have concluded that despite conflicting reports, the bulk of the evidence indicates that women devote greater time to caregiving for the elderly, compared

to men (McPherson *et al.*, 2013). The literature on gender differences in the type of caregiving tasks has also yielded conflicting findings. A distinction has been made in this literature between tasks associated with personal care such as bathing, dressing and managing incontinence, and tasks associated with management of everyday living. Some studies have found that women are more likely than men to provide assistance with tasks related to personal care (Groß & Valeberg 2015), while others have not reported similar gender differences (Kent *et al.*, 2016). Reviews on the subject have also concluded that gender differences in the types of tasks have only been reported in some but not all studies, and only for tasks related to personal-care. Female caregivers are more likely than men to carry out these tasks (Ampalam, Gunturu & Padma, 2017).

Hypothesis three which stated that age of caregivers will significantly influence caregiving burden among relatives of cancer patients in University College Hospital was accepted as younger caregivers of cancer patients reported higher caregiving burden than their older counterparts. The plausibility of this result lies in the supposition that younger caregivers (below 40 years) are often at developing stages of their careers and the inclusion of caregiving activities infringe on their routines, plans, interactions and careers. This, therefore, results in various forms of caregiving burden including health deterioration, loss of social relationships, financial cost of caregiving, stress and strain from caregiving, work/family conflict with caregiving, embarrassment from caregiving and other mental health challenges. On the other hand, older caregivers may have more time on their hands for caregiving, especially if they have fulfilled certain career expectations.

In support of the results obtained in this study, Chow and Ho (2014) found that old caregivers are more likely to report lower caregiving distress, lower depressive symptoms, and higher subjective well-being than young caregivers. Similarly, Tzeng *et al.* (2015) found that caregivers who were younger had a poor relationship with the cancer patient, experienced psychosomatic symptoms after caring for the patient, and experienced greater strains from caregiving. It should however be noted that all participating caregivers in this study reported high to severe levels of caregiving which suggests that the reduced levels of caregiving burden as described in the results of this analysis are still on the high side based on the ratings and norms of the measure used in this study.

Recommendations

Outcomes of this study recognise that family caregiving for cancer patients (and indeed all other patients with terminal illnesses) will always be an intensely personal issue. However, in furtherance of the ethical obligations of medical practitioners, as well as, in the interest of patients and caregivers, this study also recognises that family caregiving has become a critical issue of public policy. Outcomes of this study call into question practices that too often assume the availability of family caregiving without adequate support services that take into account both the individual and the family. In fact, family caregivers often feel invisible, isolated, and unprepared for the tasks they are expected to perform, and caregiving—especially when it involves an intensive commitment over the long term—carries significant costs.

It is, therefore, necessary for the government to acknowledge the role of caregiving families—to make caregiving an integral part of the nation's collective responsibility for caring for its ill population. Family caregivers are the mainstay of support for persons with a chronic, disabling, or serious health condition. In today's world, family caregivers cannot be expected to provide

complex care and support on their own. Family caregivers need greater recognition, information, and meaningful support to help them care for relatives or friends and to maintain their own health, financial security, and well-being. To that end, the researcher calls for a transformation in the policies and practices affecting the role of families in the support and care of terminally ill patients. Today's emphasis on person-centred care needs to evolve into a focus on person- and-family-centred care.

Limitations and Directions for Further Studies

There are some limitations to this study. As noted by researchers, a common concern of self-report data is social desirability (i.e. the bias in self-report data accounted for by respondents' desire to look good, which is because of the respondents' need for self-protection and social approval). Since the data for the study was collected using self-report questionnaires, the participants' responses may have been influenced by social desirability. This, in turn, might have affected the predictive power of some independent variables on the criterion variables.

The research design of this study was cross-sectional and it is thus enough to specifically infer a causal relationship. Undertaking research at one period in time can only reflect that period in time. Therefore, it would be interesting to replicate this study, with a longitudinal design, assessing individuals during different stages of caregiving role. The research only focused caregivers of cancer patients in University College Hospital; therefore the likelihood that the sample represents a good cross-section from the national population of caregivers in the country is slim.

Future research studies should make use of stratified random sampling to ensure a satisfactory representation of different groups. The use of larger sampling might also provide increased confidence that study findings would be consistent across other (similar) groups. Further studies should be more diverse and have national coverage so that economic, cultural, ethnic and geographical differences can be highlighted. Despite these limitations, these findings contribute to our understanding of the important issue of cancer patients' caregiving and highlight areas that deserve additional study.

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