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A Descriptive Study on the Quality of Life among the Caregivers of Cancer Patients Undergoing Out-Patient Chemotherapy in Cancer Care Center of Medical Center Manila (Manila Med)

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ABSTRACT

Background: Caregivers of cancer patients face unique challenges given the intense nature of the disease and its treatment, which increases their risk for burden, poor quality of life (QOL) and burnout. The issues on caregivers' burden and quality of life can be measured through the use of a multidimensional tool, Caregiver Quality-of- Life Index-Cancer (CQOLC). We determine the quality of life (QOL) of caregivers of cancer patients undergoing out-patient chemotherapy in Cancer Care Canter of Medical Center Manila (Manila Med).

Methods: A descriptive study was used with a total of 44 caregivers of cancer patients who were receiving outpatient chemotherapy completed the sociodemographic survey and Caregiver Quality of Life Index-Cancer (CQOLC) tool. The researchers identified the demographic profile of caregivers of cancer patients. Quality of life(QoL) was characterized and assessed using the CQOLC index tool.

Results: A total of forty-four (44) respondents were included in the study with mean age of 40.61. Majority of the respondents were female, young adults, and children of cancer patients. Mean total CQOLC score was 84.70 ± 21.24.

Discussion: Association between the sociodemographic factors and quality of life(QoL) impairments in each domain of family caregivers was determined of which the only domain of which has significant correlation was Burden among the female gender groups (p-value 0.0169). Caregivers whose patients belonged to non-metastatic stage cancer showed better quality of life compared to metastatic stage cancers with a p-value of 0.0315 and 0.023, on the domains of Disruptiveness and Burden, respectively. Other characteristics such as age, co-morbidities, relationship to patient, and cancer types showed no significant differences across all domains.

Interim Analysis: Caregivers of cancer patients undergoing outpatient chemotherapy in Manila Med have a relatively good quality of life based on CQOLC score. This study also confirmed that quality of life of cancer patients' primary caregivers are greatly affected by different factors.

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Introduction

Cancer is considered as a major cause of morbidity and mortality in the world. In the last few years, the number of cases have been steadily rising to a level that is of global concerns [1]. Since cancer is a chronic disease, caring load have shifted to the home, with family members often being the main care providers for cancer patients [2]. Being a cancer patient is an overwhelming experience by any individual. These trajectories have also been directed on to the caregivers providing direct care to the patients. Caregiving can vastly affect the well-being of a person. Cancer caregivers face unique challenges given the nature of cancer and treatment, which increases their risk for burden, poor quality of life (QOL), including burnouts and depression [3]. In one study done in Singapore, it was found that the caregivers of cancer patients in Singapore and other Asian countries have an impaired QOL relative to their counterparts in Europe or America [4]. Caregiving within the family depends not only on available resources, but also on existing family culture, sociocultural, religious beliefs, and the caregiver's resiliency and the capacity to withstand crises, adapt and cope [4]. Cancer caregivers' needs varies individually, depending on the patient's needs and the roles that the cancer caregivers give, both actively and passively. Family caregivers of cancer patients receive little preparation, information, or support to carry out their caregiving role.

In a study done by Harrison et al, among 60 cancer patients' caregivers, 69.1% screened positive for distress, 26.5% for depression and 34.9% for anxiety. In addition, distress among family caregivers was exacerbated with lack of patient care knowledge, access to medical and financial support [5].

In the Philippines, Panganiban et al, conducted a study in 90 Filipino caregivers of children with cancers, more than half of Filipino family caregivers were either moderately or severely dysfunctional. Majority of family caregivers experienced inadequacy from domains of social, economic and medical. Furthermore, those families whose patients were in terminal stage of cancer are more prone to go into severe and prolonged crisis and tend to experience more problems and stressors, lack of coping resources and be more dysfunctional. Filipino caregivers in overall experienced significant psychosocial distress [6].

Addressing the psychosocial needs of cancer patients' caregivers is of importance so that they can maintain their own health and provide the best possible care to the patient. Therefore, a comprehensive but also individualized approach is needed to reduce the burden experienced by cancer caregivers. Previous studies showed some of the unmet needs of the cancer caregivers not being addressed [7].

The issues on caregivers' quality of life has led to the development of scoring systems answered independently by the caregivers themselves. One of which is the Quality-of- Life Index-Cancer (CQOLC), developed by Weitzner in 1997 [8,9]. It is a multidimensional tool composed of 35-item questionnaire which was rigorously developed over time. Items in the questionnaire were rated on a five-point Likert-type scale, from 0 (not at all) to 4 (very much), and the items cover four domains: burden (psychological distress), disruptiveness (disruption of daily life), positive adaptation (social support) and financial concerns. The total score was obtained by summing up the scores of all the items (maximum score = 140). The higher score denoting better quality of life with an accepted cut off value of 80 and above based on previous studies. It was widely used and has a great utility in capturing the caregivers' quality of life.

All questions have a standard format, recognizing and assessing the physical and psychosocial problems of caregivers at the time of diagnosis, early treatment is essential to prevent symptom development. In a study by Lim et al. The CQOLC has the best psychometric properties among all disease-specific QOL measures for cancer caregivers and is used extensively worldwide [9]. The CQOLC tool has an acceptable reliability and validity demonstrating and providing efficient method of assessing the needs of the caregivers of patients with cancer [9]. Table 1 shows the content of each items in the CQOLC while Table 2 shows the corresponding items in the CQOLC four subdomains namely: disruptiveness, positive adaptation, financial concerns and burden [10].

A Meta-analysis done in 2010 by Northouse et al which assessed the physical, emotional, and social domains of a caregiver's health, showed that various interventions such as psychoeducational, skills training, and therapeutic counseling, significantly reduce caregiver burden, improving coping's ability, and improvement on the aspect of their quality of life [11,12].

Relevance of the Study

In previous studies, it has been noted that caregivers' quality of life greatly affects the quality of care being delivered to the cancer patients. These correlations were of clinical importance since the outcome, improvement of symptoms, compliance to the treatment, and possible palliative care of the patients will be addressed properly in relationship to the caregivers' quality of life. Not only the caregivers and patient will improve, but as well as the doctors, nurses, etc. will further understand the quality of life of caregivers and treatment modification based on these may be done.

Objectives

General Objective

To assess the quality of life using Caregiver Quality of Life – Cancer (CQOLC) as a parameter among caregivers of cancer patients on going outpatient chemotherapy in Cancer Care Center of Medical Center Manila (Manila Med) from July to September 2020

Specific Objectives

- To determine sociodemographic profile of caregivers of cancer patients on going out patient chemotherapy at Cancer Care Center in Medical Center Manila(Manila Med) from July to September 2020.
- To determine the association between sociodemographic factors and quality of life (QoL) impairments among caregiver of cancer patient undergoing out patient chemotherapy at Cancer Care Center in Medical Center Manila (Manila Med) using the Caregiver Quality of Life Index-Cancer (CQOLC) from July to September 2020.

Methodology

Research Design

The researchers utilized a descriptive type of study. A structured questionnaire using the Caregiver Quality of Life-Cancer (CQOLC) was used to obtain information from the caregivers. Demographic profiles of the participants were obtained from a health profile checklist selfanswered by the participants.

Sample Size

The study participants were caregivers of cancer patients seen and underwent out-patient chemotherapy at Cancer Care Center in Medical Center Manila (Manila Med) from July to September 2020. Computed sample size was 132. Inclusion criteria include adult participants (>18years old), primary caregivers of patients with cancer, regardless of stage, related up to 2nd degree of consanguinity, lives with the patient under the same household and those who can give and sign informed consent. Exclusion criteria were domestic helpers, unrelated by blood taking the role as a caregiver of the patients, known to have mental problem, presence of physical disability such as absence of one or more limbs, blindness, hearing loss, muteness, or other physical problems that affects the care being given to the patients, and all caregivers who did not give their consent. Total eligible participants were 48 caregivers using convenience sampling technique, 4 respondents declined to be included in the study.

Data Collection Process

An informed consent was given to all the participants of the study. All verbal/written questions were explained by the researchers, including the disclosure of risks/benefits for participating the study. Participant's Code was assigned per caregiver. Those who consented were asked for their demographic and health status. The questionnaire was administered by the researchers who are also medical professionals to the participants who were part of the study. The caregiver was isolated from patient throughout the interview process. No interaction with the patient regarding the survey was done to avoid any conflicts. Confidentiality of information was strictly implemented. Entire collection of data was done during their patient's chemotherapy sessions in Cancer Care Center of Medical Center Manila (Manila Med). All forms were kept according to data protection plan.

Validity

The Caregiver Quality of Life Index-Cancer (CQOLC) questionnaire content was validated by 3 Oncologist and pre tested prior to distribution to subjects.

Data Analysis

The questionnaires were collated and analyzed, descriptive statistics (i.e. frequencies, means and standard deviations) were used to characterize the demographic data. The four domains were correlated with the total score of each participant. Correlation were analyzed using a General Linear Model. Two way sample T-test and one way ANOVA were used to analyzed the correlation. p-value of <0.05 was considered significant. SAS software was used for data analysis. Among those participants who resulted with impaired domain based on the CQOLC, will be referred to a psychologist or psychiatrist for further assessment and interventions.

Ethical Consideration

Approval letter of the study was obtained last June 2020 from the Research Ethics Committee of Manila Med – Medical Center Manila with approval number MMERC No. 2020-01. Informed consent, demographic profile sheet, and questionnaires were kept in a sealed box to which only the researchers have access to. Confidentiality of the data was observed, and were destroyed with a shredder after the researchers have analyzed them. Participants were free to withdraw anytime during the period of this study.

Results

A total of forty-four (44) caregivers were included in the study. Table 1 summarizes the demographic profiles of the caregivers. The mean age of respondents was 40.61± 13.89. Majority of respondents were young adults with 57%. Thirty-six (36%) were male and sixty-four (64%) were female. Twenty-nine (29%) of caregivers have concomitant co-morbidities such as hypertension, diabetes, mental illnesses, etc. Majority of the respondents are children of the patients 21 (48%). Among the type of cancer, most of the patients have Breast Cancer (40%) followed by Colorectal Cancer with 23%. Majority of cancer patients have nonmetastatic type of cancer with 64%.

Table 1: Respondents (Caregivers) and Patients' Demographic Profile (n=44)

Respondents (Caregivers)	
Characteristics	No. (%)
Age Groups (year)	
Young adult (18-39)	25 (57)
Middle aged (40-59)	16 (36)
Elderly (≥60)	3 (7)
Gender	
Male	16 (36)
Female	28 (64)
Caregivers with Co-morbidities	
Yes	13(29.5)
No	31 (70.5)
Caregivers' Relationship to Patients	
Children	21 (48)
Spouse	15 (34)
Sibling	2 (5)
Parent	6 (13)
Cancer Patients	
Types of cancer of patient	
Breast cancer	18 (40)
Colo-rectal cancer	10 (23)
Lung cancer	2 (5)
Others	14 (32)
Cancer Stage	
Non-metastatic	28 (64)
Metastatic	16 (36)

Using the 35-item CQOLC of which the highest total possible score is 140 and denoting the higher the score the better quality of life (QoL). The mean total score of CQOLC of all the respondents was 84.70 ± 21.24. Table 2 showed the CQOLC scores to each caregiver's characteristics.

The participants' response were grouped according to the 4 domains namely disruptiveness, positive adaptation, financial concerns and burden. Using the two sample T test, gender was correlated with the 4 domains of CQOLC. The only domain which has significant correlation for gender was Burden as showed in Figure 1.

Females noted to have higher CQOLC scores indicating better quality of life as compared to Males. On the other hand, Cancer stage was correlated with four domains which showed in Figures 2. Caregivers whose patients have nonmetastatic cancer type have better quality of life in the disruptiveness and burden domains compared to caregivers of patients with metastatic type of cancers. Age, comorbidities, relationship to the patient and type of cancer did not show any significant correlation with caregivers' quality of life in any of the domains.

Total of fifteen (15) participants scored low in the CQOLC index, below 80 points indicating poor quality of life. These participants were advised to seek consult with Psychiatrist/Psychologist.

Discussion

The overall goal of the study was to assess the quality of life of the caregivers of cancer patients and determine the association of sociodemographic factors and quality of life (QoL) impairments using the domains of CQOLC.

In the present study, caregivers of cancer patients undergoing outpatient chemotherapy in Cancer Care Center (Manila Med) have a good quality of life based on CQOLC Score, this is in reference to the study of Weitzner, et al where in the higher the score the better the quality of life.(8) Comparison between the quality of life (QOL) of caregivers in other Asian countries was seen in a study of Lim et al done in 2015, showed mean total score of CQOLC in Taiwan is 81.7 ± 19.6, while in Singapore is 83.5 ± 19.1. Furthermore, nearby Asian countries such as Taiwan and Singapore, whose more developed and health system is far more advanced, caregivers' perceived their quality of life as impaired. This can be mainly attributed to post industrialization factors where in there is poorer work-life balance and increased stressors [4].

Filipino caregivers have high regard for flexibility, creativity, hard work and deep respect to elderly and terminally-ill patients.

Filipinos have a great capacity to adjust and adapt to circumstances and the surrounding environment, both physically and socially. They are highly resilient, able to withstand and cope to the burdens of taking care of cancer patients that is why Filipino caregivers perceived to have good quality of life [13].

Age as part of the demographic profile of the caregivers is also highlighted in this study. Although most of the previous studies done abroad showed an association in quality of life of the caregivers, the finding in this research showed no significance relation to quality of life across different age groups across all domains. It is further supported by another two studies done by Lim and Almutairi [4,12]. One of the reasons is could be due to most of the participants are in the young adult group (<40yo), and most of them are under less pressure to worry about their responsibilities including financial capabilities. Other reason could be due to a sample size that may have not included other age groups especially elderly.

Researchers also found out that female caregivers of cancer patients had better quality of life (QOL) than male caregivers particularly on domains of burden. This finding is consistent with the previous study done by Lim et al. which showed more impaired quality of life among male family caregivers compared to female respondents. They reported that male caregivers had impaired QOL due to a poor balance between work and family.

However, a study done by Matthews, reported lower quality of life among female caregivers and perceived more distress than male caregivers due to their traditional gender role [14]. Female caregivers scored significantly higher than male caregivers on cancer-related anxiety, fear of cancer recurrence, worry about diagnostic tests, and uncertainty about the future. However, previous studies have found out that gender of the caregiver is not a significant predictor of quality of life [15].

In a study of The Characteristics and Skills of Filipina Caregivers by Imammura which describes the characteristics of Filipina caregivers. It is very evident that female Filipino caregivers able to adjust and adapt to circumstances and any eventualities. This holds much very important in situation like being caregiver and caring for the sick and dying. The primary responsibility or obligation of the caregiver is the welfare and well-being of the sick, so it is very necessary to cope up with the demand of the changing situation. Filipina caregivers have a great capacity for diligence, hard work and industriousness. They are in fact patient and can persevere even in risky and hard conditions. These following characteristics might contribute why Filipino female caregivers had lesser burden and better quality of life compared to male caregivers [13].

This study also found out that caregivers with comorbidity and caregiver's relationship to patient regardless if primary caregiver is parent, spouse or children has a no vital role and did not affect the quality of life among caregivers of cancer patients. However, caregiver strain during the process might precipitate vulnerabilities resulting in psychological and physical health problems among caregivers [16]. Primary caregivers tend to be more prone to depression and fatigue, independent from the condition of the patient. Family caregivers not only provide the medical and physical needs of the patient but also emotional and social support adding to the demands of their daily life [17,18]. More studies are needed to better understand how family caregivers relationship influence cancer patients.

In previous studies, it was found out that there is none or weak correlations concerning the patient's cancer type or the caregiving duration with regards to caregivers' quality of life in all domains [19]. A study by Mollaei et al 2019, stated that there was no significant relationship between the type of cancer and the burden on caregivers which was also consistent with the present study [20]. Possible explanation to this is that Filipino caregivers might perceived cancer (any type) as the same entity that puts a negative psychological, emotional and physical impact on them regardless of what type the cancer may be.

Table 2: Comparison (Mean ± Standard Deviation) and Correlation of CQOLC Scores with Respect to Caregivers' and Patients' Characteristics

		Disruptiveness	Positive Adaptation	Financial Concerns	Burden
Gender	Male	12.06±5.35	23.06±4.30	5.00±2.99	20.81±8.14
	Female p -value	12.75±6.94	24.28±3.29	6.57±3.65	26.57±6.93
		0.0739	0.3388	0.1507	0.0169
Age bracket	Young adult	15.91±5.81	23.61±3.61	6.65±3.59	25.91±6.84
	Middle aged	13.69±7.25	23.75±4.23	5.50±3.01	23.31±9.04
	Elderly p -value	9.80±6.53	24.60±2.30	4.60±4.34	21.60±8.11
		0.1475	0.8666	0.3847	0.4143
Co -morbidities	Yes	12.31±7.30	24.08±3.04	6.00±4.56	23.31±17.24
	No	15.29±6.19	23.65±3.95	6.00±2.99	24.97±22.47
	p -value	0.1737	0.7269	1.0000	0.5267
Relationship with patient	Child	12.67±4.54	22.83±5.19	7.33±3.88	21.17±7.57
	Parent	16.52±6.13	23.14±3.61	6.24±3.40	26.24±6.53
	Sibling	13.00±14.14	25.50±0.71	3.50±4.95	22.50±4.95

	Spouse p -value	12.33±6.73	24.80±3.28	5.47±3.36	23.60±968
		0.2489	0.4674	0.5122	0.4965
Cancer type	Breast	12.11±6.26	23.39±3.55	4.39±2.85	21.89 +0 6.75
	Colorectal	15.80±6.99	24.90±3.29	6.90±3.25	27.60±8.92
	Lung	16.00±8.49	21.00±1.41	8.50±3.54	30.00±12.73
	Others p -value	16.14±6.38	23.93±4.29	7.07±3.81	24.79±7.31
		0.3005	0.559	0.0686	0.206
Cancer stage	Metastatic	11.47±6.27	24.53±3.60	5.27±2.96	20.80±7.66
	Non-metastatic	15.93±6.33	15.93±6.33	6.38±3.70	26.38±7.31
	p-value	0.0315	0.3297	0.3192	0.023

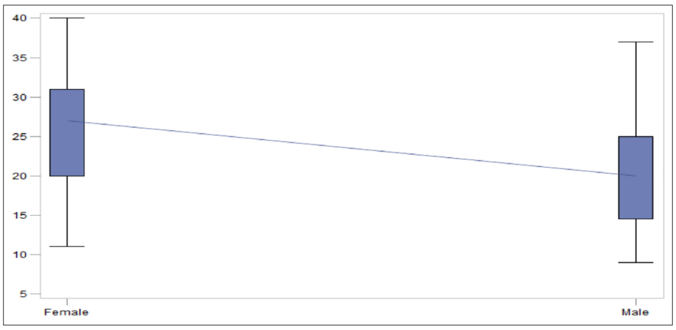

Figure 1: Correlation of Caregiver's Quality of life (Burden) to Caregiver's Gender

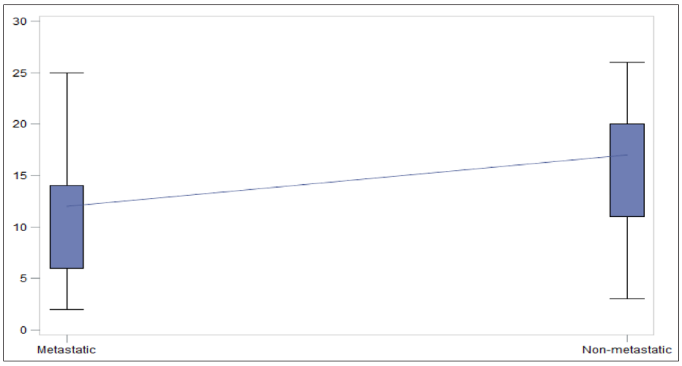

Figure 2: Correlation of Caregiver's Quality of life (Disruptiveness) to Patient's Cancer Stage

same entity that puts a negative psychological, emotional and physical impact on them regardless of what type the cancer may be. Furthermore, this study revealed a better quality of life among caregivers of patients with nonmetastatic cancer (early stage) were consistent with other previous studies. In the study of Lim et al. caregivers of advanced cancer or metastatic cancer patients understandably experienced impaired QOL in the domains of burden when compared to those caring for patients with early stage cancer or non-metastatic stage . Metastatic cancers may emphasize the difficult realities of palliative care and the patient's inevitable morta lity , which can induce stress in the family members who are involved in care planning and end -of-life issues. The results in this study is consistent with the study of Abassi et al. which states that relationship between cancer type/stage and caregiver burden has been reported to be inverse, which means that the caregiver burden was increased with increasing stage of cancer [21].

Limitations

The main limitations of the study were:

Due to pandemic, researchers were able to implement convenience sampling technique. Only caregivers who were available at the time of data collection were enrolled in the study. The sample size was only limited to 44 respondents.

The setting of the study was only conducted in a 2. single institution, and was only specific to care givers of cancer patient who were undergoing outpatient chemotherapy, thus the sample cannot represent the rest of the population

Interim Analysis

From this study, the researchers found out that the primary caregivers of cancer patients undergoing outpatient chemotherapy in Manila Med Cancer Care Center have a relatively good quality of life based on CQOLC score. This study also confirmed that quality of life of cancer patients' primary caregivers are greatly affected by different factors. Faced with overwhelming duties and responsibilities to provide support to their critically ill family member, caregivers are potentially at high risk for the development of health and well-being impairment. The findings of this study may provide basis for the development of psychosocial interventions to reduce and prevent high burden among family caregivers especially to male caregivers and those caring for advanced stage cancer.

Recommendation

For the future researchers, a larger sample size and the study be conducted in a multi center approach to be able to get the whole representation of the population. We also recommend including more factors such as caregiver income, caregivers' knowledge regarding their family members' cancer, duration of treatment etc.).

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