

## Research Article

# Family Caregivers and Caregiving Burden of Cancer Patients Khartoum State 2020

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**Introduction:** Advances in cancer diagnosis and treatment have resulted in an increase in the prevalence and a longer life expectancy. A cancer patient's family caregiver is one of the most important components of the patient's well-being. Consequently, family members have been identified as co-sufferers in the fight against malignant disorders.

**Materials and Methods:** Observational cross-sectional study conducted at specialized oncology public outpatients' clinics in Khartoum State, aimed at assessing caregiving burden among the primary family caregivers of cancer patients. To collect important data about both cancer patients and family caregivers, validated and structured questionnaires and a checklist were used. A systematic random sample was used to enrol 143 caregivers for cancer patients.

**Results:** Cancer patients were frequently females (56.6%), with 32.2 percent being between the ages of 51 and 65. Breast cancer and leukaemia were the most common kinds of cancer among individuals, accounting for 11.9 percent each. In terms of family caregivers, 54.5 percent were females with an average age of (37.7) years. Approximately half of them were cancer patients' offspring. The majority of family caregivers were married and had received secondary and/or basic education. Mean cumulative caregiver reaction assessment score was 39.8 out of 60, which revealed considered degree of sensible caregiving burden. Having more children and lower educational level were related positively to estimated caregiving burden.

**Conclusion:** Findings point to high proportions of raised level of caregiving burden.

Some family caregivers' characteristics have a role as determining factors in generating family caregiver burden.

**Keywords:** Cancer; Caregiver Burden; Family Caregiver

## Abbreviations

CRA: Caregiver Reaction Assessment; SD: Standard Deviation; SPSS: Statistical Package for the Social Sciences

## Introduction

Lately, findings of descriptive surveys implemented in Sudanese hospitals had shown the importance of cancer as the third chief cause of mortality, accounting for 5% of all deaths. Malignant disorders contribute to around 60,000 deaths every year. The incidence of cancer in Sudan shows an increasing pattern; therefore, an increasing number of populations are expected to take the role of principal caregivers in the near future [1,2].

Besides, the progress in cancer management has given rise to increased numbers of patients and prolonging of their life expectancy [3]. A family caregiver of a cancer patient is considered as one of the vital building blocks in a patient's well-being. The role of family caregiving for reducing the expenditure of the total disease cost is an additional important factor [4,5].

The word "caregiver", is a new terminology that covers a wide

variety of practices and circumstances. Caregiving may possibly be informal; comprising caring for a family member or loved one within a home-based setting, or formal caregiving which is provided by medical professionals within an institutional setting [6,7].

Quite a lot of descriptions were established with the aim of defining the caregiver burden which was challenged by a relative lack of consistency. This fact creates some sort of difficulty in summarising the concept of caregiver burden. The worst feature for family caregiver is that the person receives no financial benefit for offering care. George and Gwyther defined 'caregiver burden' as "encompassing the physical, psychological, emotional, social and financial stresses that individuals experience due to providing care". From time to time, the term informal caregiver is used to stress this conception. Classically, the family caregiver has a primary role of supporting the care recipient physically and emotionally. However, supporting the family caregiver is an important determinant of care quality in many places [8,9].

Despite a lack of homogeneity about the caregiving concept, still various models and theories are adopted to illuminate the interaction

of diverse variables through the caregiving process and to understand the caregiver burden. Generally, those variables are categorised into the following classifications: background variables, caregiver needs and demands, the psychological perception of caregivers for their own needs, the possible intermediaries between caregiver perception and actual outcomes, and finally the consequences of caregiver loads [10].

In respect to cancer family caregivers' conventional characteristics; generally speaking, it is not difficult to conclude that most of the caregivers are female, a first degree relative to the patients and most of the time they are older than 50 years [11].

Literature revealed family caregiver characteristics of cancer patients by means of the following; the majority of caregivers (63.5%) was females with mean age was 54.1 years. Frequently reported types of cancer, involved in the studies, were breast, prostate, gastrointestinal, colon, and lung. Concerning the caregiver relationship to the patient, most caregivers seemed to be spouse/partner, mature child (regularly daughters), parent, sibling, son/daughter-in-law, grandchild, niece, or friend [12].

In Ireland, a study was conducted among colorectal cancer patients and their family caregiver to identify extrapolative patients and caregivers' factors which contributed to caregiver burden. Those factors were classified into three main groups: caregiver characteristics, patient characteristics, and care-associated factors. Similarly, caregiver's burden was categorised into four core groups: family and social support, economic impact, physical health burden, and load over day-to-day activities. Significant discrepancy was detected between the four burden groups. The most adversely affected caregiving burden dimension was burden related to change regarding routine daily activities. Then it was followed by economic consequences and effect over caregiver wellbeing. The least affected dimension was the burden related to insufficient social support. Patient's characteristics were the key leading determinant of caregiving burden, explaining 14% and 22% of the burden. Care-associated elements came just after and caregivers' characteristics were the least important determinant of caregiving burden [13].

The aim of this study was to assess caregiving burden among the principal family caregivers of cancer patients.

## Materials and Methods

### Study design

A quantitative, descriptive cross-sectional design was applied. The study was conducted at specialized oncology public outpatients' clinics in Khartoum State. Actually, over 80% of cancer patients in Sudan are treated on a regular basis at the Khartoum Oncology Hospital [1,14].

### Study participants

The study included 143 caregivers whose patients had been diagnosed with cancer at least three months before the data was collected. By means of using cancer national registry, patients' selection was done by systematic random sampling. At that point principal caregiver was acknowledged as such by the cancer patient as, (the person who is mostly in charge for their unpaid, informal care).

### Data collection and measures

A face-to-face interview was administered the same day consent was attained. The following instruments were employed in the interviews: Socio-demographic Questionnaire and Caregiver Reaction Assessment (CRA). Furthermore, the medical files of patients were checked in order to document their medical information.

A structured adapted questionnaire was used to collect general data about family caregivers and cancer patients. The questionnaire had two main parts; the first part comprised demographic, social and economic information related to the family caregiver. The second part contained demographic and medical information about cancer patients. Clinical information about disease type, disease stage, and management modality was abstracted from patients' medical files.

Caregiver Reaction Assessment (CRA) is an assessment tool developed by the work of Given et al. at Michigan State University in 1992. Their effort aimed to achieve multidimensional instruments suitable for estimating burden of family caregivers of people suffering from chronic physical and psychological disorders [15,16]. (CRA) explore five domains of caregiving burden, specifically: self-esteem, lack of family support, impact on finances, impact on daily schedule, and impact on health [17,18]. The tool is acknowledged as a validated and well-structured tool to assess caregiver burden in a variety of communities and ethnic groups, with high sensitivity to identify changes over time [19,20].

### Data management and analysis

For data entry and statistical analysis, the Statistical Package for the Social Sciences (SPSS) version 20 was utilized. The socio-demographic features and caregiving burden cancer patients and primary carers were characterized using percentages, frequencies, means, and standard deviations. A two-sided P value of less than 0.05 was deemed statistically significant.

## Results

### Cancer patients' characteristics

Females made up a modest majority of cancer patients (56.6%) in the study sample when the cancer distribution was characterized by gender. The female to male ratio was 1.3:1, while in actuality, the gender distribution of cancer in Sudan was practically identical. The age distribution in the study samples mirrored that of Sudanese cancer patients of the same age. The age groups in the middle were the most affected [1,21,22] (Table 1).

Breast cancer and leukaemia were determined to be the most common cancer types, followed by lymphoma, gastric, and endometrial cancer. Similarly, with a few exceptions, this distribution replicated the typical distribution of cancer in Sudan's general population as shown by the Cancer Registry [22,23] (Table 2).

### Family caregivers' characteristics

Similar to cancer patients' gender classification, most of the family caregivers were females 54.5%, and 47.6% were young adults aged between 18 and 34 years old. The average age of family caregivers was 37.7 years. The original residence for 35.7% of family caregivers was Khartoum state. The remaining two thirds of family caregivers came from other states, mainly Aljazeera and Blue Nile states 24.5% and Kordofan 19.6%. A relatively large ratio (44.1%) of family caregivers

**Table 1:** General characteristics of cancer patients, Khartoum Oncology Hospital, 2018 (n=143).

Variable	Category	Count (%)	Mean (SD)
Age	0-17	9 (6.3)	49.1 (19.2)
	18-34	25 (17.5)	
	35-50	36 (25.2)	
	51-65	46 (32.2)	
	> 65	27 (18.9)	
Gender	Male	62 (43.4)	-
	Female	81 (56.6)	

**Table 2:** Disease related characteristics of cancer patients, Khartoum Oncology Hospital, 2018 (n=143).

Variable	Category	Count (%)	%
Type of cancer	Breast cancer	17	11.9
	Liver cancer	4	2.8
	Leukemia	17	11.9
	Lymphoma	14	9.8
	Ovarian cancer	11	7.7
	Endometrial cancer	12	8.4
	Gastric cancer	9	6.3
	Colon cancer	7	4.9
	Rectal cancer	5	3.5
	Malignant melanoma	5	3.5
	Cervical cancer	3	2.1
	Prostate cancer	3	2.1
	Nasopharyngeal cancer	4	2.8
	Oral cavity cancer	4	2.8
	Multiple myeloma	3	2.1
Others	25	17.5	
Stage of disease	Stage I	32	22.9
	Stage II	30	21.4
	Stage III	32	22.9
	Stage IV	46	32.9
Type of treatment	Chemotherapy	76	53.9
	Radiotherapy	6	4.3
	Surgery	2	1.4
	Chemotherapy + Surgery	23	16.3
	Chemotherapy + Radiotherapy + Surgery	6	4.3
	Other	28	19.9

lived with their relatives in Khartoum. Approximately 30% lived in their own houses, and 16.1% lived in rented accommodation, (Table 3 and 4).

### Estimated caregiving burden

With regards to caregiver burden, 91.6% of family caregivers reported that their activities centred on caregiving duties, 89.5% eliminated things from their schedules since starting caring for the cancer patient, and 82.5% had less visits to their families and friends.

**Table 3:** Demographic characteristics of family caregiver of cancer patients, Khartoum Oncology Hospital, 2018 (n=143).

Variable	Category	Count (%)	Mean (SD)
Age	18-34	68 (47.6)	37.7 (13.2)
	36-50	48 (33.6)	
	51-65	24 (16.8)	
	> 65	3 (2.1)	
Gender	Male	65 (45.5)	-
	Female	78 (54.5)	
Original residence	Khartoum	51 (35.7)	-
	Darfur	14 (9.8)	
	Kordofan	28 (19.6)	
	East states	7 (4.9)	
	Central and southern states	35 (24.5)	
	Northern states	8 (5.6)	

**Table 4:** Social characteristics of family caregiver of cancer patients, Khartoum Oncology Hospital, 2018 (n=143).

Variable	Category	Count (%)	Mean (SD)
Relation of caregiver to cancer patient	Father	6 (4.2)	-
	Mother	16 (11.2)	
	Son	40 (28.0)	
	Daughter	32 (22.4)	
	Brother	12 (8.4)	
	Sister	17 (11.9)	
	Husband	7 (4.9)	
	Wife	13 (9.1)	
Educational level	Illiterate	29 (20.3)	-
	Khalwa	11 (7.7)	
	Primary	30 (21.0)	
	Secondary	42 (29.4)	
	University	7 (4.9)	
	Post Graduate	24 (16.8)	
Marital status	Single	42 (29.4)	-
	Married	90 (62.9)	
	Divorced	1 (0.7)	
	Widowed	10 (7.0)	
Number of children	1-2	22 (24.2)	3.2 (2.8)
	3-5	35 (38.5)	
	> 5	34 (37.4)	

The average score of Caregiver Reaction Assessment scale was 39.8 out of 60, (Table 5 and 6).

## Discussion

The majority were middle-aged family members, with an average age of 37.7 years. Many research, done in a variety of countries, reported that the mean age of family caregivers' equivalents has risen to 50 years or more [11,12,24]. Limited exemptions in studies where the average age of the family caregiver was about 42 years [25]. The

**Table 5:** Estimated caregiving burden among family caregiver of cancer patients using Caregiver Reaction Assessment (CRA), Khartoum Oncology Hospital, 2018 (n=143).

Item	Disagree	Neutral	Agree	Mean (SD)
	Count (%)	Count (%)	Count (%)	
Felt privileged for caregiving	135 (94.4)	6 (4.2)	2 (1.4)	1.3 (0.63)
Others dumped caring onto me	82 (57.3)	2 (1.4)	59 (41.3)	2.6 (1.7)
Financial resources are adequate	65 (45.5)	16 (11.2)	62 (43.4)	3.0 (1.3)
Activities centred around caregiving	9 (6.3)	3 (2.1)	131 (91.6)	4.5 (1.5)
Difficult to obtain family help	90 (62.9)	0 (0.0)	53 (37.1)	2.6 (1.5)
Resent having to take care of patient	130 (90.9)	2 (1.4)	11 (7.7)	1.5 (0.98)
Stopped work to help patient	36 (25.2)	22 (15.4)	85 (59.4)	3.6 (1.4)
Really wanted to care for patient	142 (99.3)	0 (0.0)	1 (0.7)	1.2 (0.47)
Visited family and friends less	21 (14.7)	4 (2.8)	118 (82.5)	4.2 (1.3)
Never be able to repay patients	137 (95.8)	2 (1.4)	4 (2.8)	1.3 (0.65)
Family worked together at caregiving	109 (76.2)	3 (2.1)	31 (21.7)	2.0 (1.3)
Eliminated things from schedule	14 (9.8)	1 (0.7)	128 (89.5)	4.4 (1.1)
Family abandonment	91 (63.6)	5 (3.5)	47 (32.9)	2.4 (1.5)
Felt good about caring	136 (95.1)	4 (2.8)	3 (2.1%)	1.5 (0.66)
Difficult to find relaxation time	44 (30.8)	6 (4.2)	93 (65.0)	3.6 (1.5)
Total scale				39.8 (8.1)

discrepancy may be explained by divergence in social norms and familial milieu.

Females, as expected, played a prominent role as family caregivers, as evidenced by several studies conducted in various parts of the world [12,13,18,26] Those findings are in accordance with the woman's dominant social role in practically all cultures, regardless of community structure or country economic condition.

In the same vein, this study found that over half of the family caregivers (50.4%) were patients' descendants, and 15% were patients' spouses. Several studies, on the other hand, have shown that patients' partners and spouses are the primary family caregivers [24,26] This also demonstrates inconsistency in social customs influencing family caregivers characteristics.

According to the findings of this survey, the majority of family caregivers were married and had received secondary and/or basic education. The same conclusion had been reached by other investigations [6,16,27].

About one third 32.9% of study participants stated feeling of being left behind by their families, compared to nearly two thirds reported the opposite. Feeling of abandonment is important contributor of escalation of diverse caregiver burden. Average aggregate score of caregiver reaction assessment was 39.8 out of 60, which reflected high degree of caregiving burden.

Higher estimated caregiver burden was associated with those who have more children and lower educational grade. In literature, living with young children appears as debateable determinant of caregiver burden [28]. This enlightens the difficulty in the process of understanding of root causes of caregiving burden. Therefore,

**Table 6:** Chi square results to test significance between estimated caregiving burden and family caregiver characteristics, Khartoum Oncology Hospital, 2018 (n=143).

Item	Category	Caregiving burden		P-value
		Mean	SD	
Caregiver gender	Male	41.1	7.7	0.562
	Female	38.7	8.2	
Marital status	Single	38.6	8.5	0.203
	Married	39.9	7.8	
	Divorced	33	7.6	
	Widowed	44.2	7.6	
Having children	Yes	40.9	8.1	0.036
	No	37.9	7.7	
Educational level	Illiterate	44.7	7.9	0.001
	Khalwa	42.1	5.5	
	Primary	39.1	7.5	
	Secondary	39.1	7.5	
	University	39.9	10.2	
Occupation	Post Graduate	35	7.5	0.005
	Officer	35.3	7.5	
	Farmer	44.5	9.8	
	Merchant	38.2	8.6	
	Free worker	42.4	6.6	
	Household	38.3	7.7	
Caregiver monthly gross income	Student	38.7	13.2	0.275
	0-450	39.2	8.7	
	451-1500	41.2	7.6	
	1501-3000	41.2	7.4	
	3001-5000	36.7	9.2	

literature related to caregiver burden is rich with construction of hypothetical models endeavouring to aid simplification of caregiving phenomena [10,29]. Notwithstanding, patients and family caregiver demographic and socioeconomic factors were correlated to higher scores of caregiving burden [30].

The quantitative cross-sectional design of the study was not satisfactory regarding some concerns. It was not sufficient to give in-depth knowledge about the impact caregiving burden over family caregiver. As well to the known weakness of cross-sectional design in validating association between dependent and independent variables, inferences shown by this study should be read carefully.

## Conclusion

Results showed the classical picture of family caregivers of cancer patients is a married middle age patient ancestor who received secondary education. Also study revealed the family caregivers of cancer patients are challenging with sensible caregiver burden. Thus, prompt efforts are necessary to build up valuable preventive and alleviative interventions for this relatively frequent but; underestimated problem.

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