Research Article

Psychological Distress among Family Caregivers of Cancer Patients Khartoum State 2020

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Abstract

Introduction: The incidence of cancer in Sudan, like other world, shows an increasing pattern; consequently, a greater number of people are expected to take the role of principal caregivers in the near future. Hence, it is high time to achieve inclusive knowledge about the outcome of caregiver burden related to the caregiver's well-being.

Materials and Methods: This study is a cross-sectional, observational study aiming to assess psychological distress among the principal family caregivers of cancer patients at oncology public specialized outpatients' clinics in Khartoum State. Multiple validated and structured questionnaires and a checklist were implemented to collect relevant data related to both cancer patient and family caregiver. Systematic random sample was applied to recruit 143 of cancer patients' caregivers.

Results: Majority of cancer patients were females 56.6% and 32.2% were in the age group (51-65) years. Breast cancer and leukemia were the most frequent types of cancer among participants, with 11.9% each. Regarding family caregiver most of them were females 54.5% with average age was (37.7) years. About half of them were the cancer patient's child descendants. Concerning psychological distress among family caregivers, depression and anxiety were reported by (53.8%) and (72.7%), respectively. Psychological distress is more prevalent among caregivers with subsequent characteristics: females, younger and middle age, and lower economic status.

Conclusion: Findings point to high proportions of elevated psychological distress, among family caregivers of cancer patients. Further, longitudinal studies with qualitative dimensions are recommended. Multidisciplinary arrangements are necessary to meet caregivers' needs.

Keywords: Anxiety; Caregiver burden; Depression; Family caregiver

Abbreviations

CES-D: Centre for Epidemiological Studies - Depression Scale; POMS: Profile of Mood States; SD: Standard Deviation; SPSS: Statistical Package for the Social Sciences; WHO: World Health Organization

Introduction

Nowadays cancer is widely considered as a global public health problem and one of the primary sources of death and suffering. It affects individuals at different ages in different countries around the world, irrespective of a country's economic level or population demography. In spite of noticeable advances in the health sector and medical technology during the last thirty years, incidence rates of cancer have shown escalating trends [1-3].

In the year 2015, international statistics established the significance of cancer as a second leading cause of death, just behind cardiovascular diseases which top the list. The World Health Organization (WHO) forecasts that cancer will cause additional burdens in the near future [4].

The estimation of the incidence of the disease is projected to surge from ten million in 2000 to 27 million in 2030, above and beyond additional 17 million deaths and 75 million individuals living with malignant neoplasms, most of which are in low-income countries [5,6].

In accordance with existing statistics, cancer in Sudan shows an increasing trend during the last twenty years. Even though, no study reveals the exact reason for this trend, cancer may be associated with recurrent exposure to public and local carcinogens and to transformation in a way of living realised in Sudan. Population growth and aging also act as supplementary important risk factors [7-9].

More and more, cancer care is delivered in a home-based setting by means of the patient's family members taking up caregiving roles, supporting patients with daily activities and medical measures at home. Paradoxically, progress in cancer treatment has extended the life expectancy of cancer patients, with an expected additional load on family members [10,11].

This clears up the fact that cancer diagnosis has significant impact, not only on the patients, but also on their family members and close ones. Individuals who go through the management of malignant disorders are profoundly confronted with considerable

social, psychological, and financially draining experiences which affect those patients, alongside their families, relatives and friends [12]. The principal family caregiver is accountable for about 60-80% of the total home care received by the patient [13].

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 [14].

Family caregivers so often face a wide array of stressors, comprising transformation in day-to-day activity, family role variations, own health settings, economic and work-related pressure. Those stressors help to explain the high prevalence of clinically elevated psychological distress among cancer patients' family caregivers. Family members have been considered as co-sufferers in the fight against malignant disorders [15,16].

Healthcare experts and related institutes can greatly assist in alleviating the caregiver burden. Joint actions can be adopted to recognise, order caregiver burden and accordingly build appropriate interventions to this prevailing problem [17].

The aim of this study was to assess psychological distress in terms of "level of depression and anxiety" among the principal family caregivers of cancer patients.

Materials and Methods

Study design

A quantitative, descriptive cross sectional was applied. The study was conducted at oncology public specialized outpatients' clinics in Khartoum State. In fact, about 80% of patients diagnosed with cancer in Sudan received scheduled management at Khartoum Oncology Hospital [7,18].

Study Participants

The study sample consisted of 143 caregivers whose patients had been diagnosed with cancer at least 3 months earlier than the time of data collection. The selection of patients was done through systematic random sampling by means of using cancer national registry. Then principal caregiver was identified as such by the cancer patient "care recipient", (the person who is responsible for majority of 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, Centre for Epidemiological Studies Depression Scale (CES-D)-10 items and Reduced Profile of Mood States (POMS)-Anxiety Subscale. In addition, patients' medical files were reviewed to record patients' medical information.

General information regarding family caregivers and cancer patients was gathered using a structured modified questionnaire. The questionnaire was divided into two sections, the first of which contained demographic, social, and economic data about the family caregiver. The second section featured information on cancer patients' demographics and medical conditions. Clinical data on

disease type, stage, and management method were extracted from patients' medical records.

The CES-D-10 is considered as a satisfactory psychological measure in both healthy and mentally ill individuals. Overall scale scores vary between 0 and 30 [19-21].

The POMS questionnaire is a standard authenticated psychometric test used in research [22]. In this study, POMS anxiety subscale was implemented to minimise participant and researcher loads. (POMS) subscale scores range between 0 and 12 [23].

Data management and analysis

Statistical Package for the Social Sciences (SPSS)˙ version 20 was used for data entry and statistical analysis. Percentages, frequencies, means, and standard deviations were used to characterise demographic and medical information of cancer patients and principal caregivers' socio-demographic characteristics, level of anxiety and depression. A 2-sided P value < .05 was considered statistically significant.

Results

Cancer patients' characteristics

In this study, females made up a slight majority of cancer patient 56.6%. The female to male ratio was 1.3:1, almost similar figures were observed similar studies regarding gender distribution of cancer in Sudan. Similarly, age distribution in the study samples reflected actual same age distribution among Sudanese cancer patients. Middle age categories were the most affected groups [7,24,25] (Table 1).

Regarding to cancer type, breast cancer and leukaemia were found to be at the top of the list, followed by lymphoma, gastric and endometrial cancer. Likewise, this distribution resembled, with few exceptions, the representative distribution of cancer among general population in Sudan as revealed by Cancer Registry [25,26]. Different pattern of cancer was realized in studies conducted in other developing and developed countries in global statistics related to cancer distribution [27,28] (Table 2).

Family caregivers' characteristics

As regards to caregivers' characteristics; most of them were middle aged family members with mean age of 37.7 years old. Many studies which were conducted in several countries, demonstrated the common stream of higher average age of family caregivers' equivalents to 50 years or more [10,28,29]. Few exceptions were found in particular studies, where the mean age of family caregiver was around 42 years [30]. This could be explained by the divergences in social background and familial context (Table 3).

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

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)	

Regarding, social characteristics of family caregivers, about half of them were the cancer patient's child (mainly patient's son), about 20% were the patient's siblings, and only 14% were the patient's

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	2-Jan	22 (24.2)	3.2 (2.8)
	5-Mar	35 (38.5)	
	> 5	34 (37.4)	

Table 5: Prevalence of depression and anxiety among family caregiver of cancer patients using (CES-D) and POM - Anxiety subscale, Khartoum Oncology Hospital, 2018 (n = 143).

Item	Category	Count	%
Depression	Present	77	53.8
	Absent	66	46.2
Anxiety	Present	104	72.7
	Absent	39	27.3

spouses. Around 30% of family caregivers accomplished secondary school, one fifth finished their primary education, and an equal portion received no formal education (Table 3).

Family caregivers' psychological distress

By using Shortened Centre for Epidemiological Studies-Depression Scale and Profile of Mood States-anxiety subscale, depression was established in more than half of the family caregivers 53.8% and anxiety in 72.7%, (Table 4).

Discussion

Nearly this study revealed the same epidemiological picture of cancer in Sudan with regard age distribution, gender affiliation and cancer type and management modality [7,31].

Expectedly, females had dominant contribution as a family caregiver which was supported by many studies completed in different parts of the globe [10,30,32,33]. Those results were consistent with the leading social role of the woman almost in all cultures, irrespective of

Table 6: Chi square results to test significance of association between depression status among family caregiver and family caregiver characteristics, Khartoum Oncology Hospital, 2018 (n = 143).

Item	Category	Not depressed Count (%)	Depressed Count (%)	P.value
Caregiver gender	Male	31 (47.7)	34 (52.3)	0.433
	Female	35 (44.9)	43 (55.1)	
Caregiver age	18-34	32 (47.1)	36 (52.9)	0.333
	36-50	18 (37.5)	30 (62.5)	
	51-65	14 (58.3)	10 (41.7)	
	>65	2 (66.7)	1 (33.3)	
Marital status	Single	21 (50.0)	21 (50.0)	0.736
	Married	41 (45.6)	49 (54.4)	
	Divorced	0 (0.0)	1 (100.0)	
	Widowed	4 (40.0)	6 (60.0)	
Caregiver monthly gross income	0-450	18 (36.0)	32 (64.0)	0.058
	451-1500	17 (42.5)	23 (57.5)	
	1501-3000	15 (50.0)	15 (50.0)	
	3001-5000	7 (53.8)	6 (46.2)	
	5001-10000	6 (85.7)	1 (14.3)	
	>10000	3 (100.0)	0 (0.0)	
Household monthly gross income	0-450	3 (33.3)	6 (66.7)	0.023
	451-1500	9 (31.0)	20 (69.0)	
	1501-3000	14 (38.9)	22 (61.1)	
	3001-5000	12 (44.4)	15 (55.6)	
	5001-10000	18 (60.0)	12 (40.0)	
	>10000	10 (83.3)	2 (16.7)	

Table 7: Correlation between depression status and anxiety status, Khartoum Oncology Hospital, 2018 (n = 143).

Item		Depression	Anxiety
Depression	r	1	0.710**
	P-value		<0.001
Anxiety	r	0.710**	1
	P-value	<0.001	

**Correlation is significant at the 0.01 level (2-tailed).

community structure or economic status of the country. Furthermore, the leading economic role of men may appear as a factor to inhibit their caregiving role. This economic justification can possibly be supported by the result that, more than one third of family caregivers were households.

In the same context, this study showed that almost half of the family caregivers were patients descendent 50.4% and 15% were patients' spouses. Inversely, several studies revealed that patients' partners and spouses are the chief family caregivers [16,28]. This point shows another area of discrepancy in social norms that regulate the characteristics of family caregiver.

In this study, depression was reported by 54% of family caregivers. This result is aligned with the depression prevalence established in equivalent studies, which demonstrated a variation in depression

prevalence between 40% up to 60% [15]. However, some studies revealed prevalence of depression among family caregivers less or more than above stated range [34]. Generally, studies had displayed a widespread of depression prevalence among family caregivers; e.g. a wide-range from 4.5% to (82.2%) [35].

On the other hand, anxiety was more prevalent among family caregivers. It was reported by (73%) of participants. This result was relatively high compared to similar studies. For instance, an American study revealed anxiety prevalence of 42.2% and an Indian study showed anxiety prevalence of 53% [34,36].

Depression among family caregivers was correlated to household income, whereas anxiety was interconnected to caregiver gender, age and income. Psychological distress is more prevalent among caregivers with subsequent characteristics: females, younger and middle age and with lower economic status, this was in keeping with existing literature [15]. Higher prevalence of psychological distress among females may be explained by the fact that women carry out different family tasks besides caregiving job [34,37].

This study showed that, psychological distress (depression and anxiety) among family caregivers was positively correlated to each other. Anxiety and depression symptoms are common negative psychological consequences that emerge from cancer caregiving. In comparison to the general population, family carers have reported higher levels of anxiety and depression [38]. Individual and social rules that may not line up with or emotionally support the patient and family experiencing and responding to the many core symptoms of depression, such as depressed and abrupt mood swings, anhedonia, and sometimes uncontrollable and violent outbursts, are likely to complicate the caregiving experience [33].

This study, however, had some limitations. Firstly, although the standardized tools used in this study to assess different aspects of family caregiver burden are very much valid and reliable in many societies, limitation may be present when addressing tool's reliability on Sudanese population. This issue may be a concern to construction of the tool, a selection of variables, diagnostic criteria and cut off points.

Secondly, some of individual criteria which may affect caregiving burden, particularly level of psychological distress such as personal trait and personality type were not measured. Deficiencies in time and application complexity of those measurements were major constraints.

Conclusion

The findings point out an elevated psychological distress among family caregivers of cancer patients, with relative to recognizable high anxiety level. Numerous patients' and family caregivers' qualities have a role as determining factors in generating family caregiver burden. At the level of policy formulation, multidisciplinary arrangements are necessary to adopt firm regulations to meet caregivers' psychological requirements. In addition, timely strengthening of oncology centres to offer specialized service to family caregiver of cancer patients is crucial.

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