

Impact of demographic, clinical and psychological variables of patients and caregivers on the perception of burden among the family caregivers of patients with cancer

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Abstract

The study aims were to assess the level of burden among caregivers of patients diagnosed with cancer and to examine patient and caregiver variables associated with high levels of burden.

A descriptive cross sectional study was performed at the Psychiatric Department in the University Hospital of Monastir, Tunisia. The study included a total of 138 dyads of patients and their corresponding family caregivers. The dyads were convoked then examined. The data were assembled using questionnaires elaborated by the research team and caregiver burden was measured with the Zarit Burden Interview. Patients completed the Hospital Anxiety and Depression Scale and the KATZ Index of Activities of Daily Living.

About one third of the caregivers experienced high levels of burden. The scores at the Zarit Burden Interview ranged from 15 to 70 and mean score was 48.7 (SD =18.2). This negative outcome of caregiving was found to be related to both patients' and caregivers' variables. Statistically, the factors associated to high levels of burden among family caregivers that are linked to the patient's profile were: male gender, age between 61 and 70 years old, having other medical morbidities, necessitating pre and post-operative chemotherapy, having intermediate to high levels of anxious or depressive symptoms and a severe functional impairment. Caregivers who helped their patients to accomplish many daily activities were found to be high-burdened. The caregiver variables that were found to be related to high levels of burden among caregivers were: male gender, age between 40 and 59 years old, employed full-time status, being the child of the patient, having another member of the family needing daily care, caregiving period more than one year, and not resorting to a professional healthcare at home.

The current study demonstrates the importance of a systematic assessment and early intervention procedures needed in order to detect vulnerable caregivers.

Highlights

- Family caregivers of patients with cancer experience high levels of burden as a consequence of care.
- Family caregivers of those patients may have to accomplish many additional personal, professional and household tasks that may major their distress.
- Healthcare providers need to assess burden of care and identify the most vulnerable caregivers.

Introduction

Cancer is a serious disease that needs a long period of treatment and a continuous care in order to help patients physically, psychologically and financially. So that, confronting a cancer diagnosis impacts deeply not only the patient but also his family members. Usually, alongside the professional assistance, cancer care is provided by family members who help the patient during medical and daily activities, from the first symptoms to recovery or death [1-3]. Major advances have been made in the treatment and have led to increase survival rates and cancer is more likely considered as a chronic disease requiring more care outside the hospital setting.

Although some studies focused on the benefits of caregiving experience, most researchers [4-6] suggest that caregivers constitute a

vulnerable population described to be more exposed to fatigue, anxiety, burden psychological distress depression, psychological distress and low quality of life [7-12]. They seem to have a higher predisposition to medical illnesses and a greater risk for mortality [13-18]. Caregiver burden is considered to occur when the emotional or physical health of caregivers is threatened or when their available resources are overwhelmed by the care demands [19]. Burden seems to be common in family caregivers, with a lack of interventions targeted to support caregivers [20]. Recent researchs have been made aimed at evaluating the role of family caregivers in the field of oncology, but the impact of caregiving remains infrequently described because the available studies focus on the patient's pain and suffering [21,22].

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Purpose

The purpose of the current study was to investigate evaluate the caregivers' burden among a population of adult family caregivers taking care of patients diagnosed with cancer and to investigate the effect of demographic, clinical and psychosocial characteristics of patients and caregivers on the burden of family members caring for patients with cancer.

Methods

Research design

The current study was performed using a cross-sectional, descriptive and correlational design for patients and their families after a recent diagnosis of cancer. The sampling procedure was done using the consecutive sampling approach.

Participants and setting

The first patients' selection was made in the University Hospital Fattouma BOURGUIBA departments' taking care of patients with cancer, and was based on medical diagnosis of a cancer. Those departments were respectively: surgery, gastroenterology, gynecology, urology and nephrology departments. Patients who accepted to continue the study were referred to the main investigator, who met them in the psychiatric department in University Hospital Fattouma BOURGUIBA, Monastir, Tunisia.

The study sample included Arabic speaking dyads of patients who have been diagnosed with cancer and their corresponding caregivers. All patients were adults (≥ 18 years old), Arabic language speaking, had a sufficient level of communication. They have perceived the diagnosis of the cancer since at least four weeks prior to the study. Patients were hospitalized during the study period actually or have been previously hospitalized. They were requested to participate to the study, then asked to design their primary family caregiver. The family caregiver was nominated by the patient, and judged to be the principal provider of non paid care to the patient. All caregivers were older than 18 years old, Arabic language speaking, had a sufficient level of communication.

Instruments

Demographic data about patients and caregivers were obtained during a first data collection review. This included gender, age, duration of caregiving, relationship between the patient and the caregiver, marital status, professional status, habitation status, the existence of other dependent persons particularly children in care and the need of a professional care at home. This included nurses' visits, bathing assistance, having adaptative and orthopedic equipments and sessions of physical therapy. Medical data about patients were obtained from medical records. Concerning tumor classification, the researchers have been referred to the classification of the American Joint Committee for Cancer Classification [23]. Patients diagnosed at the stage I were considered to be diagnosed at an early stage.

Burden assessment: Caregivers completed the ZARIT Caregiver Burden Scale in order to evaluate the burden, in the validated and translated version in Arabic language [24].

Depression and anxiety assessment: Patients completed the Hospital Anxiety and Depression Scale (HAD Scale), in the translated and validated version into the Arabic language [25,26].

Dependence assessment: Patients completed the KATZ Index of Activities of Daily Living (ADL) in Arabic language [27].

Data analysis

Biostatistics staff of the department conducted and provided statistical analysis. Categorical variables are assessed and classified to describe the study's sample. Quantitative variables were calculated with averages and standard deviations (SD). Qualitative variables were expressed using percentages. Data was analyzed using Pearson correlations. Independent t tests were used to assess the link between psychometric variables and socio demographic ones. Statistical analyses were conducted using SPSS version 20.

Results

Descriptive statistics

Sample Characteristics

Table 1 presents the socio demographic characteristics of the study sample.

Table 2 displays the characteristics of the caregiving relationship according to the caregiver. About 66% of patients lived with their caregivers at the same home, and only 14.5% of caregivers used to refer to a professional healthcare at home.

Clinical data about patients are presented in table 3. Breast cancer was the most frequent localization (45.7%).

Patient anxiety and depression symptoms

The results of the evaluation of anxiety and depression among patients were represented in the table 4. The total score for the two items ranged from 12 to 37 with a mean of 20.5 ± 5.5 . Scores of anxiety ranged from 6 to 17 and the mean score was 9.7 ± 2 . Scores of depression ranged from 6 to 20 and the mean score was 10.8 ± 3.5 . Table 5 displays the distribution of the patients according to anxiety and depression subscales.

Participation of patients in activities of daily living

Mean score of the KATZ Index of Activities of Daily Living participation was 4.6 ± 1.4 , and all the scores ranged from 2 to 6. Fourty

Table 1. Sociodemographic characteristics of the study sample

Sample	Characteristics	n	%	
Patients	Gender	Male	46	33.3
		Female	92	66.6
	Age Range (years)	30 to 39	19	14
		40 to 49	19	14
		50 to 59	47	34
		60 to 70	53	38
Total		138	100	
Caregivers	Gender	Male	69	50
		Female	69	50
	Age Range(years)	20 to 39	33	24
		40 to 59	88	64
		60 to 70	17	12
	Marital status	Married	120	87
		Single or Separated	18	13
	Employment Status	Employed full-time	70	51
		Retired	9	6
		Not employed	59	43
	Educational attainment	Primary	45	32.6
High School		29	21	
University		21	15.3	
Total		138	100	

Abbreviations: n_number, %_percentage.

seven percent of the patients had a severe functional impairment. Fifty three percent had a moderate impairment to full functioning.

Caregiver burden

Using the ZARIT Caregiver Burden Scale to assess the caregiver burden, the scores ranged from 15 to 70 and mean score was 48.7±18.2. Table 6 shows the distribution of the levels of burden among caregivers. About one of every three caregivers perceived severe levels of burden.

Univariate analyses: Factors associated to high levels of caregiver burden

Factors statistically associated to high levels of caregiver burden are listed in table 7. Male gender for both patients and caregivers is

Table 2. Characteristics of the caregiving relationship according to the caregiver

Characteristics		n	%
Familial relationship	Wife-husband	44	32
	child	58	42
	child in law	11	8
	Mother or father	12	9
	Brother or sister	13	9
Cohabitation with the patient	Yes	91	66
	No	47	34
Professional Healthcare at home	Yes	20	14.5
	No	118	85.5
Caregiving period	Less than one year	49	35.5
	One to two years	67	48.5
	Two to four years	18	13
	More than four years	4	3
Daily care of another member of the family	Yes	73	53
	No	65	47
Total		138	100

Abbreviations: n_number, %_percentage.

Table 3. Clinical data about the patients sample

Variable		n	%	
Cancer localization	Breast	63	45.7	
	Colorectal	36	26	
	Kidney	15	10.9	
	Uterine cervix	12	8.7	
	Prostate	8	5.8	
	Pancreas	4	2.8	
Cancer stage	Early	31	22.5	
	Late	107	77.5	
Chemotherapy	Preoperative	19	13.8	
	Pre- and postoperative	119	86.2	
Comorbidities	Yes		92	66.6
		One	27	19.6
		Two or more	65	47
	No	46	33.3	
Total		138	100	

Abbreviations: n_number, %_percentage.

Table 4. Evaluation of the anxious and depressive symptoms among patients

Variable	X	SD	Minimum	Maximum
G-HADS-D	10.8	3.5	6	20
G-HADS-A	9.7	2	6	17
G-HAD-scores	20.5	5.5	12	37

Abbreviations: G-HADS-A: Hospital Anxiety and Depression Scale-Arabic version-Anxiety subscale, G-HADS-D: Hospital Anxiety and Depression Scale-Arabic version-Depression subscale, X: Median scores value, SD: Standard Deviation

Table 5. Distribution of the levels of anxious and depressive symptoms among patients

Variable	Low levels (0 to7)		Intermediate levels (7 to 10)		High levels (more than 10)	
	n	%	n	%	n	%
G-HADS-D	41	29.7	23	16.7	74	53.6
G-HADS-A	11	8	80	58	47	34.1

Abbreviations: G-HADS-A: Hospital Anxiety and Depression Scale-Arabic version-Anxiety subscale, G-HADS-D: Hospital Anxiety and Depression Scale-Arabic version-Depression subscale

Table 6. Distribution of the levels of burden among caregivers

Variable	Low		Moderate		High	
	n	%	n	%	n	%
Burden levels	20	14.5	77	55.8	41	29.7

Abbreviations: n_number, %_percentage.

Table 7. Variables associated with high levels of burden among caregivers

Variables	n	%	p- Value
Patients socio demographic characteristics	Male gender	44	95.7 <10 ⁻³
	Age between 61 and 70 years old	45	32.6 <10 ⁻³
Caregivers socio demographic characteristics	Male gender	57	41.3 <0.01
	Age between 40 and 59 years old	71	51.4 <10 ⁻³
	Employed full-time status	54	39.1 <0.05
Characteristics of the caregiving relationship according to the caregiver	Being the child of the patient	38	27.5 <10 ⁻⁴
	Caregiving period more than one year	72	52.2 <10 ⁻⁴
	Having an another member of the family needing daily care	51	37 <10 ⁻⁴
	Not having a Professional Healthcare at home	88	63.8 10 ⁻³
Clinical variables of the patients	Pre- and postoperative chemotherapy	91	65.9 <10 ⁻³
	Having co morbidities	83	60.1 <10 ⁻³
Levels of anxious and depressive symptoms among patients	Intermediate to high levels of anxious symptoms	93	67.4 10 ⁻³
	Intermediate to high levels of depressive symptoms	95	68.8 <10 ⁻³
Levels of impairment among patients	severe functional impairment	64	46.4 10 ⁻³

Abbreviations: n-number, %_percentage.

associated to a higher level of burden. The age of patients above 61 years seems to be considerably burdensome. For the caregiver, being the child of the patient, aged between 40 and 59 years old, married, employed full-time, having an another member of the family needing daily care, are factors considered to be binding. It appears that a period of care giving more than one year and the failure to obtain a professional healthcare at home are associated to a high level of burden among caregivers.

Discussion

The study had various advantages. First, our sample was diverse in socio-demographic characteristics. Second, this study differed from previous research by assessing the variables of the dyad patient-caregiver related to high levels of burden. Third, it moved from assessment of the impact of social resources on caregiver outcomes to test the influence of taking into account the psychological patient distress and his functional abilities. However, the study is limited by its cross-sectional design. It was conducted at a single clinical site, among a sample of patients and their primary caregivers, so caution must be used when generalizing results from this sample to other patient

caregiver populations. Although participants were from different communities, the study population was not ethnically and culturally heterogeneous. The data were measured at one point in time, giving only an actual illustration of the primary caregiver experience. Time since diagnosis may have had a consequence on the variables that was not captured. In addition preexisting psychological distress among caregivers such as anxiety and depression may have had an influence on the actual results.

As treating successfully cancer is difficult and complex, the experience of caregiving is also too hard and can lead to various repercussions on a caregiver's life [28,29]. The current study provided an estimation of the caregiver burden and investigated the effects of both caregiver and patient variables on caregiving burden. It corroborates the existing literature and provides an advance in the field of oncology.

High levels of burden were found in one third of patients caregivers. Previous studies have concluded also that 20 to 32 % of caregivers perceived themselves as highly burdened [30-33]. Recent recommendations in medicine suggest focusing attention and providing care not only to patients but also to their families. Yet, challenges facing family members as caregivers seem to be neglected in some institutions. The family-centered care model, developed in the field of pediatrics [34], becomes gradually more emerging in oncology settings. Logan noted that although palliative care services aim to assist both patients and their families, family members are not receiving the needed psychosocial support [3].

This study revealed interesting associations, and caregiving burden was elucidated by the variables of the dyad patient-caregiver. As such, burden levels were found to be higher among male patients, aged between 61 and 70 years old, having other medical morbidities, necessitating pre and post-operative chemotherapy, having intermediate to high levels of anxious or depressive symptoms and those with a severe functional impairment. In the literature, similar results concerning gender differences among patients were found [19,35]. Hagedoorn et al. [36] reported that men often report distress and consequently seem to be attentive to their emotions, particularly when they are ill.

In the literature, gender differences concerning patients was explained by a lower attention given to emotions by men, they seem to express their psychological distress less than women [37,38] Lutzky and Knight [37] supported partially this explanation. However, different evidence exists in other studies, taking care of a female patient with cancer was linked to more advantageous outcomes [29]. A lower attention is given to emotions by men, they seem to express the psychological distress less than women [37,38] Few studies focused on the examination of burden among caregivers of older cancer patients [4]. Older adults with cancer seem to be rapidly exposed to functional deterioration, which leads to inescapable greater responsibilities devoted to caregivers. Furthermore, older people have often other morbidities and need an increased care and support that may top up caregiver burden [33]. Our results were not consistent with those of Hsu et al. [39] which reported that 15% of caregivers of older patients with cancer experienced high levels of burden. Given the growth of the aging population, a better comprehension of the particular challenges facing those caregivers is required [40,41].

Caregivers of patients having other medical morbidities and of those necessitating pre and post-operative chemotherapy were found to have higher levels of burden. In fact, comorbidities may predispose to physical frailty [40], and combined symptoms. The number of symptoms with a consequent increase in patient's demands is associated

with caregiver distress [42,43]. At the same time as patients' symptom distress increases, and causes deteriorations in his quality of life [44,45] functional limitations increase and caregiver responsibilities increase too. Patients necessitating pre and post-operative chemotherapy are those necessitating more support and management. If the disease is advanced, patients need heavier treatments and family assistance increases as the patient's disease advances and the patient's physical status worsens. Caregivers have different psychological reactions to patient symptoms, which can cause distress as the failure of the patient's health [46]. Objective burden, as compared to subjective one, is more associated with patient disease and treatment-related conditions [47].

Caregivers who perceived patients as being more dependent with their ADL were more likely to encounter higher levels of burden. These results are consistent with prior studies which noticed that caregivers of cancer patients who need more daily help had higher levels of burden [48,49].

Other studies have demonstrated that a patient's level of dependence increases the mischance for caregiving burden [29,50-52]. In fact, decline in the patient's functional status greatens the amount of tasks with which the patient requires aid. Caregivers who must assist with many tasks which may be difficult or demanding may have higher levels of distress [2,43,53-55]. In addition, caregiving obligations may restrain the caregiver's capacity to engage in different activities in the society [56]. Williams [57] reported that the burden experienced by family caregivers who assist patients only in instrumental tasks is different than that experienced by family caregivers who provide the patients physical and psychological assistance. Obviously, it was demonstrated in several studies that the patient's physical limitations is linked to the decline in cancer family caregiver physical health and can lead to the negative perception of the caregiving experience including the sense of burden [7,58-60].

The current study revealed that higher levels of caregiver burden were associated to caregiver's characteristics which are: male gender, age between 40 and 59 years old, employed full-time status, being the child of the patient, having an another member of the family needing daily care, caregiving period more than one year, and not resorting to a professional healthcare at home. The gender difference in burden may mirror the gender difference nearly found in the normal population [61-64]. In this study, the negative effect of caregiving was shown to be higher in men, which is in conformity with previous evidence, stating that husbands were more burdened than wives [49]. Opposing evidence exists also reporting that female caregivers perceive more distress than male ones [29], [65] and supporting the 'identity-relevant stress' hypothesis. Female partners of patients with cancer were feeling insecurity and incompetence. As earlier described in literature [49], older caregivers experienced higher levels of burden. Older caregivers have frequently co-morbid conditions, resulting in frailty and decreased physical aptitude [30], particularly those who are previously vulnerable [66]. Limitation of family resources and social relationships can lead to problems for older caregivers; they take distance gradually from familial and social interactions to become totally focused on providing care. However, other studies have shown that older caregivers experience less psychological distress resulting from caregiving [15,59]. The explanation is that older caregivers perceive caregiving roles to be less demanding and their activities restricted comparatively to younger caregivers [12]. According to the results of the current study, caregivers who were employed full-time were more likely to have high levels of burden. This is concordant with studies that have concluded that demands from both caregiving

and work become overwhelming [52,53,67-70]. The reprioritization of responsibilities related to caregiving tasks, home-care demands and work obligations may increase the caregiver distress [52,68,70]. A recent study carried by Leonidou and Giannousi [71] focused on the experiences of caregivers of patients with metastatic cancer showed that work life burden interested 29% of the participants. Different work difficulties were described and have led caregivers to search solutions that permit them to be nearer to the patient and to have more time for caregiving. Family caregivers reported that they use to switch shift from full-time to part-time work in order to accomplish their caregiving responsibilities [7].

On the other hand, other researchers [31,72] suggested that employment can be protective for caregivers [73-75] because it can be an important source of financial earnings and social assistance [75]. While two studies showed no distinction in caregivers' issues between workers and non-workers, other studies [29,73,74] found that not employed family members experienced more caregiving burden than employed caregivers. The familial relationship to the patient was determinant in caregiving outcomes. It was mentioned in literature that the impression of being abandoned, which is a part of caregiver burden was more widespread among adult children caregivers [76]. Renegotiating factors related to intergenerational relationships may increase the distress levels [52,68,70]. Whereas, other studies reported that spouses were more distressed than other caregivers [53,54,77], because they use to serve the most extensive help, preserve their role longer, and endure greater amount of tasks. Having another member of the family needing daily care, and notably children was found to be associated to greater levels of caregiver burden. In fact, burden may be linked to the relinquishment of responsibilities and obligations. Duties related to childcare and the rearrangement of home-care demands increase the caregiver strain [52,68,70].

A critical requirement exists to develop appropriate interventions to support the caregiving role for family caregivers of patients with cancer. Most crucially, oncology nurses need to guarantee that caregivers obtain the proper and pertinent resources and advocate assistance for their parents. Oncology nurses may use these helpful and precious recommendations on conducting a comprehensive caregiver assessment that serve to improve support for caregivers in cancer [78].

Conclusion

In the present study, caregivers reported high levels of care burden. Several variables should be considered while evaluating the care roles, serving to accompany closely patients diagnosed with advanced cancer. Precipitating or hurtful and protective factors should be checked out actively in order to co-predict caregiver burden, which needs to be more actively and systematically investigated. Particular attention should be given to the changes of these variables as changes happen in a patient's condition or as caregiver become distressed.

Conflict of interest statement

All the authors certify that they have NO affiliations with / or involvement in any organization or entity with any financial interest (such as honoraria; educational grants; participation in speakers' bureaus; membership, employment, consultancies, stock ownership, or other equity interest; and expert testimony or patent-licensing arrangements), or non-financial interest (such as personal or professional relationships, affiliations, knowledge or beliefs) in the subject matter or materials discussed in this manuscript.

Authorship statement

All authors have made substantial contributions to all of the following: (1) conception and design of the study; (2) drafting and/ or revising the article critically for important intellectual content; (3) final approval of the submitted version.

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