



# Proximology in a Cancer Care Setting in Burkina Faso: A Study of Cancer Patient Caregivers

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**Abstract:** We carried out this study in order to promote holistic management of cancer patients in our context by taking account of the burden of caregiving on the patient's family and friends. It was a cross-sectional, observational study of 72 patient/caregiver dyads that included patients followed at Yalgado Ouedraogo University Hospital, Ouagadougou, Burkina Faso, for at least one month as outpatients for confirmed cancer and their primary caregiver from May-October 2021. A survey questionnaire was used as a guide for a standardized interview of the primary caregivers. The variables collected from the caregivers related to sociodemographic characteristics, the relationship of the caregiver to the patient and the caregiver's level of information concerning their patient's disease. The roles taken on by the caregivers were collected. Caregiver burden was assessed using the Caregiver Reaction Assessment questionnaire (CRA). Mean scores of the CRA dimensions were compared according to selected patient/caregiver characteristics. Mean age in the patient group was 52.6 years and in the caregiver group 41.4 years ( $p = 0.00001$ ). The majority of patients were women (72.5%) whereas the majority of caregivers were men (69.3%). Salaried employees were more numerous in the caregiver group (45.2%) than in the patient group (17.7%) ( $p = 0.001$ ). In 53% of dyads, the relationship was parent/child. Administrative formalities and emotional support were the main tasks undertaken by the primary caregivers. Strength of the parental bond, living in the same home, and knowledge of the seriousness of the patient's illness had a significant impact on CRA scores. In our setting, we need to reflect on measures to lighten the burden of the cancer patient's caregiver.

**Keywords:** Patient Caregivers, Cancer, Proximology, Burkina Faso

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## 1. Introduction

The advent of cancer significantly disrupts the physical appearance, psychological state and social relationships of the person concerned because of the chronic and serious nature of the disease [1]. Treatment requires numerous hospital visits and admissions of varying duration. Organization of daily life and role distribution in the cancer patient's family are disrupted to meet the demands of their management and treatment [2]. A new relationship of interdependence is created between the person who has

become a patient and their family members. The quality of this relationship takes on increasing importance in patient management [3]. Proximology, a new field of research that made its appearance at the beginning of the 21st century, deals with study of the relationships between the sick or dependent person and their close relatives [4]. Close family members may be involved in patient management in various ways, one of the most important being the caregiving role. The term "patient caregiver" applies to any person who takes care on a daily basis of a sick or dependent relative, whatever the relative's age [5]. Interaction between caregiver and

patient is a major parameter as it affects the patient's quality of life as well as the quality of care given at home and in the hospital [6].

The caregiver, however, may be prey to direct or indirect distress related to their role. Cancer gives rise to a series of emotions involving fear, anger, sadness, despair or disappointment that are shared by the caregiver, as well as by all those close to the patient [7]. The probability that the outcome may well be fatal also has a considerable impact on the caregiver's quality of life, as much as on that of the patient. Making family members part of holistic management of the cancer patient is not only a wish expressed by the majority of families, but also a recognized need [3].

In Burkina Faso, a country in the heart of sub-Saharan Africa, there is a major lack of social protection characterized by the poor ability of individuals and households to cope with the consequences of unforeseen events (such as illness, job loss or natural catastrophes) [8]. Forty percent of total health expenses are borne by the inhabitants, who pay for care when they attend health centers [9]. Cancer is a public health problem in such a context. The needy circumstances of the populations and the limitations of the medical and technical facilities weigh even more heavily on the prognosis of disease. Resources are insufficient and in such circumstances family caregivers compensate for the shortcomings of provisions for patient care and assistance. Average weekly time spent in care for sick persons is 41.9 minutes for male caregivers and 45.4 minutes for female caregivers [10]. In addition, because of social inequalities, average weekly time spent preparing meals for the household is 426.7 minutes for women compared with 14.7 minutes for men. Average weekly time spent on domestic tasks is 117.6 minutes for women compared with 8.6 minutes for men [10].

The city of Ouagadougou is growing rapidly. Public transport in the urban environment is underdeveloped [11] and people often use personal transport. Sixty percent of households possess a means of transport. In 80% of cases, this is two-wheeled, whether motorized or not [11].

Yalgado Ouédraogo University Hospital is in the city center, at a distance from the residential areas which are concentrated in the periphery [12]. It is the oldest hospital in Ouagadougou. Like more recent and more modern hospital centers, the inefficient spatial organization of the care facilities, the lack of appropriate signage and the absence of means of access to the various departments (such as lifts, access ramps) considerably limit the accessibility of these services to illiterate persons and/or those with reduced mobility [13]. Patients often need help to overcome these obstacles. The presence of a caregiver at their side makes it easier for them to move around within the hospital and to settle bills in the payment office.

In Burkina Faso Nor has there been any study of the expectations of cancer patients and the role of primary caregivers. We carried out this study in order to promote holistic management of cancer patients in our context by taking account of the burden of caregiving on the patient's family and friends. The aim of the study was to analyze the

proximological dimensions of the role of caregivers of cancer patients in the cancer department of Yalgado Ouédraogo University Hospital Center. Our work may serve as a basis for reflection on how caregivers' needs could be better managed and supported in a context where the function of caregiver has no formal recognition.

## 2. Patients and Methods

This cross-sectional descriptive study carried out from May to October 2021 included the caregivers of patients with confirmed cancer who had been followed for at least one month as outpatients in the cancerology department of Yalgado Ouédraogo University Hospital, together with their primary caregivers.

### 2.1. Tools

A survey questionnaire was used as a guide for a standardized interview of the primary caregivers. The questionnaire underwent preliminary testing in 10 patient-caregiver dyads. The study project was then submitted to and approved by the national ethics committee.

### 2.2. Participant Recruitment

This was a convenience sample of primary caregivers of consecutive patients recruited during the medical oncology consultations. The informed consent of each patient/caregiver dyad was obtained from them together and recorded on a consent form. In our study we addressed the primary caregiver, that is, the person mainly responsible for looking after the patient.

### 2.3. Conduct of the Interview

The interviews took place in a dedicated room and the anonymity of the respondents and the confidentiality of their responses was ensured. The responses of the caregivers were not passed on to the patients. The variables collected from the caregivers related to sociodemographic characteristics, the relationship of the caregiver to the patient and the caregiver's level of information concerning their patient's disease. The roles taken on by the caregivers were collected through open questions: "What is your role as a caregiver in the hospital?", "What is your role when you are a caregiver at home?", "What is your role as a caregiver in other places?" The patients' characteristics were collected from their medical records.

### 2.4. Analysis of Variables

Categorical variables were described as proportions. These proportions were compared between the two groups (patient group and caregiver group) by the McNemar test (non-parametric test for matched series). Quantitative variables were described as means, standard deviation and range. Student's *t* test was used to compare the mean ages of the two groups. Post-coding was carried out for analysis of the responses to the open questions regarding the roles assumed

by the caregivers. These roles were identified consensually by the research team and then categorized and classified according to the various types of social support as proposed by House et al. [14]: emotional support (expression of positive affect, empathy, providing comfort, protection); appraisal support (recognition of skills and values); informational support (advice, suggestions, passing on knowledge, interpretation); material or instrumental support (practical assistance, tangible services rendered). Caregiver burden was assessed with the Caregiver Reaction Assessment (CRA) taking into account the positive and negative dimensions of the caregiver's reactions, scored from 1 to 5 [15]. Mean scores obtained for each dimension of the CRA (schedule disruption, financial problems, lack of family support, health problems and impact on self-esteem) were compared for the various parameters by the Wilcoxon-Mann-Whitney test for categorical variables with two categories and by the Kruskal-Wallis test for categorical variables with more than two categories. The age variable was differentiated into two categories (younger than 40 years, 40 years and older) before comparison with the mean score of each dimension of the CRA.

The Cronbach alpha coefficient of the CRA for our study was 0.65, indicating questionable internal consistency.

### 3. Results

We included 72 patient/caregiver dyads. Mean age in the patient group was 52.6 years and in the caregiver group 41.4 years ( $p = 0.00001$ ). The majority of patients were women (72.5%) whereas the majority of caregivers were men (69.3%). Salaried employees were more numerous in the caregiver group (45.2%) than in the patient group (17.7%) ( $p = 0.001$ ). The characteristics of the two groups are shown in Table 1. The relationship between patients and their primary caregivers was filiation (parent/child) in 52.8% of cases, marital (spouse/spouse) in 22.2% of cases, siblingship (brother/brother or brother/sister) in 11.1%, and other relationships (uncle/nephew or niece, cousin/cousin) in 8.3%. No relationship existed between the patient and the primary caregiver in 5.6% of cases. In our patient group, breast cancer accounted for 55.6% of cases, colon cancer 16.7%, lung cancer 8.3%, ear, nose and throat cancer 6.9%, stomach cancer 5.6%, cancer of the limbs 4.2% and ovarian cancer 2.7%.

**Table 1.** Sociodemographic characteristics of the patient and caregiver groups.

Variables	Patients		Caregivers		p value**
	n	%	n	%	
Age (years)					
< 40	13	18.1	40	55.6	< 0.0000
≥ 40	59	81.9	32	44.4	
Gender					
Male	23	31.9	50	69.5	< 0.0000
Female	49	68.1	22	30.5	
Married					
Yes	63	87.5	55	76.4	0.11
No	9	12.5	17	23.6	
Employee					
Yes	13	18.1	33	45.8	0.001
No	59	81.9	39	54.2	
Occupation					
Homemaker	24	33.3	4	5.5	--
Informal sector*	15	20.8	31	43.1	
Public service employee	10	13.9	19	26.4	
Retired	12	16.7	1	1.4	
Farmer/grower	4	5.5	5	6.9	
Student	4	5.5	10	13.9	
Unemployed	3	4.2	2	2.8	

\* Workers in the informal sector; \*\* McNemar test.

With regard to caregiver recruitment, 70.9% volunteered spontaneously, 24.2% were selected by a third person with their consent, and 4.9% were caregivers by necessity (they stated that they had had no choice). Caregivers who were designated were often appointed by the family together with the patient (80%). They were designated because of their availability (46.7%) or their family relationship with the patient (53.3%). For those caregivers who were volunteers, the family relationship was the main motivation for volunteering.

Nearly all caregivers (98.4%) were aware of their patient's disease. They had been informed by physicians in 68.8% of

cases and by the patients themselves in 16.4%. For 40% of caregivers, their patient's disease was serious, while 11.3% were not aware of how serious the disease was. Sixty-four caregivers (88.9%) thought there was a possibility that their patient would be cured.

In a hospital setting, 36 caregivers self-attributed a role of emotional support, 46 a role of instrumental support, and 22 a role of informational support. Instrumental support consisted of help with administrative formalities (50%), help with transport (36.1%) and help with care (4.2%).

In the home, 25 caregivers self-attributed a role of emotional support, 28 a role of instrumental support, and 19 a

role of both emotional and instrumental support (Table 2). Instrumental help related to cooking and housework (41.7%), treatment supervision (19.4%) and help with care and nursing (13.9%).

**Table 2.** Roles assumed by caregivers with regard to their patient.

Setting	Roles	n = 72	%
Hospital	Instrumental support (n = 46)		
	1) Administrative formalities	36	50.0
	2) Help with transport	26	36.1
	3) Help with care	3	4.2
	Emotional support (n = 36)		
	Providing comfort, positive affect	36	50.0
	Informational support (n = 22)		
	1) Interpretation	19	26.4
Home	2) Advice, suggestions	5	6.9
	Instrumental support (n = 47)		
	1) Cooking, housework	30	41.7
	2) Treatment supervision	14	19.4
	3) Care and nursing	10	13.9
	Emotional support (n = 44)		
	Providing comfort, positive affect	44	61.1
	Instrumental support (n = 54)		
Other settings	1) Various tasks	50	69.4
	2) Requesting financial assistance	5	6.9
	Emotional support (n = 7)		
	Providing comfort, positive affect	7	9.7

In other settings, 54 caregivers self-attributed a role of instrumental support and 7 caregivers self-attributed a role of emotional support. Instrumental support consisted of various tasks not directly related to care in 69.4% of cases. Eleven caregivers stated that they had “no role outside the hospital and the home”.

**Table 3.** Mean scores of the impact of the caregiving role on Caregiver Reaction Assessment (CRA) dimensions according to caregiver characteristics.

Caregiver variables	CRA dimensions														
	Self-esteem			Schedule disruption			Health problems			Financial problems			Lack of family support		
	M	SD	p	M	SD	p	M	SD	p	M	SD	p	M	SD	p
Gender															
Male	3.42	0.46	0.49	3.20	0.77	0.77	3.29	0.49	0.83	3.35	0.64	0.0	2.64	0.63	0.32
Female	3.51	0.53		3.11	0.92		3.32	0.48		3.09	0.82		2.53	0.60	
Age (years)															
< 40	3.44	0.46	0.94	3.04	0.71	0.08	3.24	0.52	0.26	3.25	0.67	0.5	2.52	0.50	0.39
≥ 40	3.45	0.55		3.34	0.91		3.38	0.43		3.30	0.75		2.72	0.74	
Salaried employee															
No	3.38	0.53	0.19	3.18	0.90	0.80	3.24	0.53	0.28	3.39	0.61	0.4	2.62	0.56	0.89
Yes	3.53	0.43		3.17	0.70		3.38	0.41		3.13	0.79		2.60	0.69	
Married															
No	3.45	0.57	0.85	3.00	0.74	0.27	3.28	0.59	0.99	3.04	0.61	0.0	2.48	0.69	0.24
Yes	3.44	0.47		3.23	0.83		3.31	0.45		3.35	0.72		2.65	0.60	
Relationship to patient															
Parent/child	3.52	0.44	0.22	3.34	0.70	0.32	3.44	0.43	0.04	3.26	0.73	0.5	2.67	0.59	0.28
Marital	3.46	0.51		3.00	0.94		3.30	0.45		3.40	0.81		2.64	0.52	
Sibling	3.41	0.57		3.25	0.98		3.10	0.30		2.96	0.72		2.60	0.91	
Other	3.36	0.38		2.77	0.72		3.08	0.49		3.28	0.39		2.20	0.22	
None	2.86	0.61		2.75	1.01		2.75	0.84		3.50	0.33		2.67	0.59	
Living arrangement															
Other home	3.36	0.50	0.39	2.73	0.71	0.007	3.19	0.62	0.36	3.27	0.65	0.9	2.25	0.58	0.005
Shared home	3.47	0.48		3.31	0.80		3.34	0.43		3.27	0.73		2.72	0.59	
Seriousness*															
Known	3.63	0.32	0.001	3.30	0.47	0.11	3.38	0.49	0.02	3.40	0.77	0.0	2.68	0.63	0.11
Not known	3.34	0.54		2.92	0.95		3.15	0.42		3.03	0.48		2.46	0.58	

M, mean; SD, standard deviation; p, p value; \*, seriousness of patient's disease.

Responses to the CRA are presented in Table 3. The mean score for impact on self-esteem was significantly higher when the caregiver was not aware of the seriousness of the disease (3.63 vs 3.34, p = 0.001). The mean score for

schedule disruption was significantly higher when patient and caregiver shared the same home (3.31 vs 2.73, p = 0.0007). The mean score for caregiver health problems was significantly higher when there was no family relationship

between patient and caregiver ( $p = 0.04$ ). The mean score for financial problems was significantly higher in non-salaried workers than in salaried workers (2.56 vs 2.34,  $p = 0.04$ ). It was significantly higher when the caregiver was aware of the seriousness of the disease (3.40 vs 3.03,  $p = 0.03$ ). The mean score for lack of family support was significantly higher when the patient and the caregiver lived in the same home (2.72 vs 2.25,  $p = 0.005$ ).

## 4. Discussion

This study sheds light on the profile of caregivers of cancer patients in a setting where the status of patient caregiver is not formally recognized. In our setting, the status of primary caregiver is either voluntary or by designation. The majority of caregivers in our study were volunteers, which could be explained by the family relationship between them and the patient. Voluntary caregivers generally gave their parent/child or marital relationship as the reason why they volunteered.

Nearly all caregivers knew of their patient's diagnosis. Awareness of their patient's illness is an asset for the caregiver, who can increase their knowledge of the disease, ask the care team relevant questions and better identify what is involved and what is at stake in their caregiving role. In this way, the caregiver becomes better able to meet their patient's expectations. In addition, our study showed that the majority of caregivers surveyed were not aware of the seriousness of their patient's disease. Their lack of knowledge of cancer could be harmful for the patient, leading to underestimation of the disease and of some aspects of patient management. Good communication between the care team, the caregiver and the cancer patient is of capital importance to guarantee quality care [16, 17].

We found that caregivers took on a variety of roles. In a hospital setting, their main role related to management of care and administrative formalities. In our institution in Burkina Faso, in order to receive care the patient must undertake formalities such as making appointments, settling bills at the payment office, and registering on the patient list. He or she must be able to carry out the paraclinical investigations requested and obtain the drugs and consumables necessary for treatment. This may involve numerous trips within the same hospital or between several hospitals, as well as long waits of which patients may not be capable because of loss of autonomy. Help with administrative formalities thus falls to the caregivers who, in our setting, do this naturally.

The second role reported by caregivers was giving their patient emotional support. Medical consultations or care provision in a hospital environment (chemotherapy, radiotherapy, surgery, support care) can be a source of fear, stress and discomfort. It is important for the patient to be reassured by the presence of a familiar face and to know that they are accompanied and supported [18]. Regrettably, in our study only 30.6% of caregivers were aware of the patient's need for emotional support.

The third role reported by the caregivers was interpreting during medical consultations. In our environment, educational level is low and there is often a linguistic barrier between the patient and the care team. The caregiver acts as interpreter, translating and explaining what is said, and so supports the care team in their advice and recommendations on treatment and the patient's lifestyle. To do so, caregivers may need to have a higher educational level than the patients. This was often the case in our study, and may have motivated the caregiver's volunteering or being designated for this role.

In the home, the principal role taken on by the caregivers was help with domestic tasks. Many patients have total or partial, permanent or temporary loss of independence, so caregivers tend to assist in tasks such as laundry, cooking and housework [19].

Emotional support is also needed in the home, which is often the place where the patient can express their emotions, fears and apprehensions.

As well as help with domestic tasks and emotional support, there is health care at home to be managed. As our patient group were treated as outpatients, their caregivers became supervisors ensuring that treatments at home were properly carried out. They motivated patient compliance and prevented forgetfulness that would have negatively affected adherence. In addition, caregivers assisted with personal care. Often however, they were not trained for these tasks which require certain skills and specific knowledge of cancer [20].

In other settings, caregivers were entrusted with various errands for patients who could not carry them out themselves. This increased the workload of caregivers, with possible repercussions on their social relationships, availability to look after their own family and to cope with their own job. Here emotional support takes on a different form. Cancer is a disease that carries stigma, even more so when there are visible physical signs [21]. Support from caregivers becomes extremely important for the patient's psychological health. The caregiver's role consists of attenuating these psychological repercussions and acting as a shield that protects the patient from the gaze of society.

We found no relationship between gender, age, salaried status, marital status and the five dimensions of the CRA. On the other hand, parental bond, sharing the same home, and knowledge of the seriousness of the disease were associated with certain dimensions.

The caregiver's health was less affected when they had no family link with the patient and more affected when there was a parent/child link. As the emotional bond between a child and their ascendants is very strong, the child who is a caregiver could be more sensitive to their parents' state of health. The caregiver may suffer physically from fatigue, muscle pain or worsening of a pre-existing health condition [22]. This has an impact on the patient's own state of health, as shown by Grunfeld [23]. However, caregivers tend to conceal or understate their difficulties and needs in relation to those of their sick relative. They do not wish to seem weak or complaining, through fear of giving the impression that they are not properly assuming their caregiving role [24].

When the caregiver shares a home with the patient, schedule disruption is even greater. All aspects of their life are affected by the caregiving role. Personal and leisure activities take second place and priority is given to care of the patient. Professionally, the caregiver's repeated absences from work are detrimental. In a number of developed countries, particularly in France, legal measures define and facilitate the role of caregiver to a sick person. Salaried employees who are caregivers have a legal status that enables them to be absent from work to assist an increasingly dependent relative, and this status is not subject to length of job tenure and has no effect on income [25]. We found that the mean score of the lack of family support dimension was significantly higher when patient and caregiver shared the same home. In these circumstances, the attention of the other family members is generally taken up by the patient, who occupies the emotional space. Other family members may no longer perceive the malaise and personal needs of the caregiver, who finds themselves neglected. Lack of family support may lead to a feeling of isolation and abandonment, and the impression that the other family members are avoiding their responsibilities. The feeling of being abandoned, together with the strong psychological demands of their role, can have repercussions on the caregiver's health. Awareness of the seriousness of cancer was the factor that had an impact on the greatest number of dimensions of the CRA. It had the strongest impact on the health of the caregiver and on their finances, leading them to invest all their resources in the management and treatment of the patient. In our setting where there is no universal health coverage, the cost of cancer treatment is borne entirely by the patient and their family. Knowledge of the severity of the disease raises the awareness of the family and relatives, who all come together in support and contribute financially to the patient's care. The primary caregiver becomes the main actor in financial management, and their own resources often serve to make up the shortfall. With regard to the caregiver's own health, knowledge of the seriousness of the patient's disease makes them psychologically more vulnerable and more prone to social isolation, depression and stress.

## 5. Conclusion

In Burkina Faso, primary caregivers were nearly always family members, the relationship being generally parent/child or by marriage. The caregivers' self-attributed roles varied according to the context in which these roles were undertaken. Administrative formalities, emotional support, domestic tasks and participation in care were the tasks most often taken on by the primary caregivers. The strength of the parental bond, living in the same home and knowledge of the seriousness of the patient's disease were the factors that had the greatest impact on the primary caregiver. These must be taken into account in order to enable caregivers to preserve an acceptable quality of life. In our setting, we need to reflect on the measures to be taken to lighten the burden of the cancer patient's caregiver.

## Disclosure Statement

The author has no competing interests to declare.

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