

# Coping and Caregiving-Satisfaction among Caregivers of Patients with Cancer at the Uganda Cancer Institute and Mbarara Regional Referral Hospital in Uganda

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## Abstract

This study aimed at investigating the relationship between coping and caregiving satisfaction among informal cancer caregivers in Ugandan referral hospitals. A convenient sample of 436 consenting informal care givers aged 18 years and above were interviewed; a cross-sectional design was used. Because of the difficulty in defining a fixed population for this category of care givers, whoever was found at the bed side meeting the inclusion and exclusion criteria were recruited into the study. A tri-dimensional coping scale (namely; problem solving, denial and venting) was used to measure coping. After controlling for all the relevant covariates (Patient's age, sex of care giver, education of caregiver, respondent's age, respondent's education level, respondent's education, respondent's country of origin, respondent's religion, stage of cancer, score on burnout scale), the venting aspect of coping had a significant effect on caregiving satisfaction ( $F = 1.83$ ,  $P\text{-value} = 0.03$ ). The above covariates accounted for 41.3% of the variability in care giving satisfaction scores ( $R^2 = 0.413$ ). Venting as a coping mechanism had a significant effect on caregiving satisfaction. There is need to pay attention to the coping strategies of informal cancer caregivers to enhance their care giving experience. There is need to help caregivers develop healthy coping methods as they participate in cancer care.

## Keywords

Coping, Caregiving Satisfaction, Cancer Givers, Uganda

## 1. Introduction

Coping is a major issue in cancer care globally. Coping is the process of managing needs and challenges brought about by a person's inner and outer experiences, applying cognitive and behavioral efforts to solve personal and interpersonal problems, and in the quest to manage and reduce stress [1]. Coping controls distress that comes with the stressful situation, as well as the management of problems causing strain by directly altering factors that stress [2]. Coping strategies are learned [3], and therefore, caregivers that receive training on coping are satisfied, characterized by better and effective coping approaches [4] [5]. Studies demonstrate that caregivers of cancer patients apply several coping approaches to cope with the challenges that they experience [6] [7] [8]. The coping approaches used more often by caregivers of cancer patients include active planning, looking for external support, religious refuge, acceptance of cognitive restructuring, and avoidance isolation [9]. Notably, caregivers of cancer patients are usually associated with worsening health outcomes during the diagnosis stage of the disease; however, their health tends to improve when they get acclimatized much better as they expand on their responsibilities of caregiving and utilize effective coping approaches [10].

Active planning includes participating actively, increased active inputs and generation of action plans that solve several challenges, and beginning to act on something instantaneously [6]. This form of planning enables carers' of cancer patients to be more active, develop active plans, solve problems steadily and accept the problem in order to find new solutions when tackling the problem at hand [6]. Several studies done demonstrate that carers' showing positive problem abilities experience limited stress [7]. However, this calls for increased sensitization among carers' with sufficient information on active planning, improved coping skills, particularly in regard to problem-oriented stress, in order to achieve satisfaction [2].

The role of coping in enhancing caregiving satisfaction in cancer care is not well understood. Caregivers are vital in the cycle of cancer treatment because they help the patient to perform activities such as self-care, movement, transport, communication, household chores, shopping, cooking, financing, organization of appointments, social activities, help the patient to cope with symptoms and coordination of medical care [8] [9], amidst numerous challenges such as change in their physical capability, body functionality, appearance, job status, sexual functions and roles, which generally are associated with worsening health outcomes [9] [10] [11] [12]. However, their health tends to improve when they get acclimatized much better as they expand on their responsibilities of caregiving and utilize effective coping approaches [9] [11] [12]. Studies demonstrate that caregivers of cancer patients apply several coping approaches, which in many times are learned while dealing with the challenges they experience [3] [13] [14] [15] [16]. Coping mechanisms have been categorized as problem-focused and emotion-focused coping strategies [17] [18] [19]. Problem-focused or active

coping approach is aimed at finding solutions to challenges, while emotion-focused or passive or avoidance coping approach is aimed at managing emotions [2] [20].

Majority of the caregivers have no idea on how much care the patient needs, how to use the available resources, have inadequate information regarding the disease, the care required and have limited support which makes them neglect their own health and depict inadequate coping reactions [10]. Studies that revealed that caregivers' health habitually deteriorates during the diagnosis period of the disease and improves when they adapt to their role of caregiving. The adaptation to caregiving involves the use of effective coping methods so as to cope up with the difficulties they experience [16]. Karabulutlu [7], in his study found that the coping attitude used most frequently by family caregivers was active planning, and the least used coping attitude was avoidance isolation. However, some caregivers displayed ineffective coping attitudes. Aydogan *et al.* [21] in their work pointed out that caregivers utilized mainly the "acceptance" method among the "emotional coping" methods. This study aimed at determining the effect of coping on the caregiving satisfaction of cancer caregivers in Uganda.

## **2. Methods**

### **2.1. Study Area and Setting**

The study was conducted at two tertiary care facilities in Uganda namely Uganda Cancer Institute in Kampala City and Mbarara Regional Cancer Centre in Mbarara City (Western Uganda). The Uganda Cancer institute is a specialized tertiary teaching public facility in Kampala central business district. Mbarara is a regional referral public University hospital approximately 268 km south west of Kampala city.

### **2.2. Study Design**

This study employed a cross-sectional design.

### **2.3. Study Participants**

The study participants were consenting adult caregivers of patients with cancer (Age 18 years and above). A caregiver in this study was defined as an informal care giver who spends a substantial amount of time caring for the patient. Such a person should have played this role for at least one week.

### **2.4. Inclusion Criteria**

Caregivers of patients diagnosed with cancer at any stage, regardless of the type of cancer, who were accessing care at the Uganda Cancer Institute and Mbarara regional referral hospital were included in the study. The caregivers had to be 18 years old or above and had to give written consent. The caregivers had to have provided care to the cancer patient for at least a week.

## 2.5. Exclusion Criteria

Participants were excluded if they were less than 18 years of age and if for whatever reason, they could not answer the questionnaires. Those that were approached and declined to participate were excluded.

## 2.6. Sampling Method

The study used convenient sampling approach. Given that informal caregivers tend to be mobile, (a single patient could have several caregivers) it was not possible to create a sampling frame. Whoever was therefore found giving care at the time the interview and fulfilling the inclusion criteria was included in the study. They were consecutively recruited until the sample size was accrued.

## 2.7. Study Instruments

Two instruments were used namely the Adjusted Caregiver reaction assessment scale (ACRA) and the coping orientation to problems experienced (COPE). The ACRA is a 5-point likert scaled tool with 7 response items. Responses range from “strongly agree” to strongly disagree. It measures the extent to which caregiving affects self-esteem. Items assess whether caregiving is rewarding and enjoyable or whether it causes resentment. Items include statements such as; “I enjoy caring for my partner. Its constructs were found to be valid and internal consistency reliable ( $\alpha = 0.9$ ) [22].

The COPE is one of the validated and most frequently used to measure coping and has been utilized in various populations. It is an abbreviated version of the original COPE. It is a multidimensional self-report instrument which consists of 52 items, namely self-disclosure, active coping, denial, substance abuse, seeking emotional support, seeking instrumental support, behavioral disengagement, venting, positive reframing, planning, humor, acceptance, religion, and self-blame [23].

Both instruments were subjected to structural validation and internal consistency reliability testing using a sub-sample of the respondents. ACRA was found to be a bi-dimensional scale with an internal consistency reliability scores of 90% and 79% (Alpha = 0.9 & 0.79).

The COPE was found to have three subscales; subscale 1 which was named problem solving, subscale 2 which was named denial and subscale 3 which was named active coping. Subscale 1 had an internal consistency reliability coefficient of 0.91, subscale 2 had 0.92, and subscale 3 0.91.

## 2.8. Data Analysis

The composite indices developed through structural validation and internal consistency reliability testing were used to generate scores for participants. These scores were used in subsequent analyses. The mean scores and standard deviations were determined and used to examine the relationship between coping and care giver satisfaction using multiple linear regression modelling. Group

differences were compared using ANOVA.

### 3. Results

#### 3.1. Sample Characteristics

A total of 436 care givers participated. The male: female ratio was 1:2.1. The average age of the males was 37.3 years (standard deviation = 12.2) and that of the females was 33.5 years standard deviation = 34.7). The differences in age were significant ( $t = 3.181$ ,  $P\text{-value} = 0.002$ ). The majority of the care givers were from rural households (65%) followed by semi-urban (17% and urban (16%) households.

Of the 436 respondents, 94% were Ugandan, 1.4 were South Sudanese, 1.52% were Rwandese, 0.9% each were Tanzanians and Kenyans. Congolese and Burundians were 5.0% and 7.0% respectively.

Majority (39.9%) of the care givers were farmers, followed by business people (26.6%). The gender differences in occupation were significant ( $\chi^2 = 19.1$ ,  $P = 0.014$ ). The rest of the socio-demographics are summarized in **Table 1** below.

#### 3.2. Coping Experiences of the Respondents

The mean total score of the respondents on the care giving satisfaction (COPE) scale was 2.9 (standard deviation = 0.53); the mean for the males was 2.99 (standard deviation = 0.48) while that for the females was 2.85 (standard deviation = 0.55) respectively.

#### 3.3. Care giving Satisfaction Experiences of Respondent

The average total score of the respondents on the adjusted caregiver reaction assessment scale was 3.58 (standard deviation = 0.69). The average total score for males was 3.64 (standard deviation = 0.69) while that for the females was 3.55 (standard deviation = 0.69).

#### 3.4. Relationship between Coping and Caregiving Satisfaction

After controlling for all the relevant covariates, all the domains of coping (problem solving, denial and venting) do not influence caregiving satisfaction on the first subscale of the caregiving satisfaction scale but the coping domain of venting ( $P = 0.0360$ ,  $f = 1.83$ ) influences caregiving satisfaction on the second dimension of the caregiving satisfaction scale as summarized in **Table 2** below.

### 4. Discussion

We set out to determine the effect of coping on the caregiving satisfaction of cancer caregivers in Uganda. The study found that cancer care giving is mainly done by younger female and older male peasants followed by business people.

There was a significant relationship between coping and caregiving satisfaction. The findings are consistent with earlier ones by [24] [25] where caregivers

**Table 1.** Socio-demographic characteristic of respondents.

Variable	Male	Female	Overall	Test stat	P-value
Age of care giver (Mean, SD)	37.3 (12.2)	33.5 (11.4)	34.7 (11.8)	3.181	0.002
Age of patient (Mean, SD)	38.0 (24.1)	32.0 (22.7)	35.4 (23.6)	2.506	0.013
Occupation (% , N)			-	19.114	0.014
Farmer	59 (34.3)	113 (65.7)	173 (39.9)		
Business	32 (28.6)	80 (71.4)	113 (26.0)		
Others	49 (0.0)	98 (100)	1 (0.23)		
Distance to nearest HC (% , N)			-	7.298	0.199
Less than 20 Km	12,164 (37.2)	228,108 (62.7)	349,172 (40.1)		
More than 20 Km	18 (24)	57 (76)	75 (17.6)		
Non-Response	1 (14.2)	6 (85.7)	7 (1.62)		
Education level (% , N)			-	20.730	0.004
Primary level	47 (29.94)	118 (70.0)	157 (36.94)		
Secondary school level	50 (29.31)	97 (70.69)	147 (27.29)		
Completion of certificate Course	22 (37.92)	36 (62.07)	58 (13.65)		
University Education	11 (40.74)	20 (59.26)	31 (6.35)		
Non Response	10	30 (16.7)	40 (1.39)		
Disability (% , N)			-	1.702	0.427
No	136 (32.5)	282 (67.5)	420 (97.7)		
Yes	4.0 (40)	6.0 (60)	10 (2.3)		
Non Response	0 (0.0)	3.0 (100)	3 (0.69)		
Level income (000) (Median, range)	309710.7 (402374.1)	276182.6 (555397.6)	150,000 (300 - 5,000,000)	0.588	0.557
Religion (% , N)			-	16.417	0.006
Anglican	62 (41.6)	87 (58.4)	152 (36.1)		
Roman Catholic	49 (33.3)	98 (66.7)	147 (34.9)		
Moslem	5 (11.4)	39 (88.6)	44 (10.5)		
Born Again	19 (26)	54 (74)	73 (17.3)		
Seventh Day Adventist	1 (20)	4 (80)	5 (1.2)		
Non Response	4 (30.7)	9 (69.3)	13 (3.01)		
Type of CA (% , N)					
Breast Cancer	11 (31.4)	24 (68.6)	35 (8.1)		
Co rectal Cancer	6 (40)	9 (60)	16 (3.7)		
Prostate Cancer	13 (48.1)	14 (51.8)	27 (6.2)		
Cervical Cancer	18 (27.7)	47 (72.3)	65 (15.0)		

**Continued**

Leukaemia	28 (35.4)	51 (64.5)	80 (18.5)		
Head and Neck Cancer	14 (31.8)	30 (68.2)	45 (10.4)		
Childhood Cancer	2 (12.5)	14 (87.5)	16 (3.7)		
Not Known	48 (31.6)	102 (68.4)	150 (0)		
Stage of CA (% , N)				-	10.495 0.033
Early Stage	37 (45.1)	45 (54.9)	82 (19.3)		
Late Stage	35 (34.3)	67 (65.7)	104 (24.4)		
Terminal Stage	11 (31.4)	24 (68.6)	36 (8.5)		
Not Known	57 (26.1)	155 (73.9)	213 (47.9)		

**Table 2.** Relationship between coping and care giving satisfaction.

Outcome variable	Exposure variable	Covariates adjusted for	F-statistic	P-value	R <sup>2</sup>	Adjusted R <sup>2</sup>	Root MSE		
First dimension of caregiver satisfaction	Coping • Problem solving • Denial • Venting	Patient's age,				0.0503	5.5834		
		sex of care giver,	1.75	0.0516	0.4406	0.0188	5.9008		
		education of caregiver,	1.44	0.1490	0.3913	0.1254	5.3080		
		respondent's age,	1.44	0.1395	0.3694	0.0742	5.7521		
		respondent's education level,				0.0658	5.7733		
		respondent's education,				0.0658	5.7733		
		respondent's country of origin,				0.0658	5.7733		
		respondent's religion,				0.1894	5.4367		
		stage of cancer,				0.1194	5.3218		
		score on burnout scale,				0.1125	5.6409		
		score on satisfaction scale							
		Second dimension of caregiver satisfaction	Coping • Problem solving • Denial • Venting	Patient's age,				0.3683	4.8534
				sex of care giver,	1.67	0.0650	0.4094	0.1522	5.4778
				education of caregiver,	1.68	0.0670	0.4141	0.1779	5.4259
respondent's age,	1.83			0.0360	0.4130	0.2188	0.2188		
respondent's education level,						0.1815	5.2859		
respondent's education,						0.1815	5.2859		
respondent's country of origin,						0.1815	5.2859		
respondent's religion,						0.1643	4.9730		
stage of cancer,						0.1680	5.2759		
score on burnout scale,						0.1865	5.2994		
score on satisfaction scale									

who use coping strategies were more likely to experience increased intimacy and affection, personal development, improved close relationships, satisfaction, social support by other individuals and self-respect than those who did not. Ineffective coping exposes caregivers to physical, psychological, emotional, social and economic problems [25].

These findings are in support of studies conducted by [10] [24] [25] [26] who also found that there existed a positive significant relationship between coping

and caregiving satisfaction. Karabulutlu [10] found that increased use of active planning would lead to increase in caregiving satisfaction and that use of avoidance isolation would cause stress among caregivers. The findings of this study are also in support of findings by [26] who found that religious coping was associated with higher levels of care giving satisfaction.

Research by Kasuya *et al.* [24] and Toseland *et al.* [25] also support the findings of this study where findings indicate that increase in the use of effective coping attitudes like active planning, acceptance cognitive restructuring, seeking external aid and religious asylum lead to increase in care giving satisfaction. Other studies done have shown that deliberate coping leads to higher life satisfaction [27].

This life satisfaction could most likely influence caregiving satisfaction with more life satisfaction leading to caregiving satisfaction. Further research has shown that caregivers who cope positively are more likely be more successful in finding meaning in caregiving. Caregivers who are able to find meaning and purpose in their role tend to have positive outcomes [25]. The positive outcomes include caregiving satisfaction. Contrary to this study's findings, Savard *et al.* [28] found that caregiving satisfaction was derived not from coping per se but from caregivers receiving information, advice, or emotional and or social support. Similarly, in another study conducted by [29] results showed that there existed a negative relationship between coping and care giving satisfaction as increased use of avoidance coping would lead to a reduction in caregiving satisfaction. The reason coping may or may not lead to caregiving satisfaction among different individuals is that according to Arnold's cognitive appraisal theory, despite exposure to similar or identical stressors, individuals often exhibit distinctive cognitive appraisals of stressors based upon individual perceptions of stressors; the physiological change merely supplements the responsive experience [30]. This means that these individuals will cope differently which in turn means that they will experience different caregiving outcomes including caregiving satisfaction.

Conspicuously, the effectiveness of various coping strategies is contentious [31] [32]. For instance, both problem-focused and active strategies and emotion-focused or passive or avoidance strategies may be theoretically different, but they are used in several distressing situations, and can lower psychological stress [33]. Also, It is not only coping strategies that are effective against stress on caregivers [34].

Much as how coping specifically venting as a coping mechanism has been demonstrated to influence caregiving satisfaction in this study, it is likely that there is no coping mechanism specific to cancer care giving and that the mechanisms individuals use to cope with any other stressful situations in their lives is most likely the same as they would use while cancer caregiving which will depend on a number of factors and other individual psychological resources.

### **Future Research**

It is recommended that similar research be conducted for a sample of child care-

givers who form a significant percentage in Uganda. The new sample however should consist of an equal number of male and female caregivers. This will reduce the current concern of results portraying female perceptions instead of cancer care-givers perceptions in general.

There is need for longitudinal studies to examine coping across the caregiving trajectory right from diagnosis to demise and through survivorship in order to provide a clearer understanding of the progress coping processes of caregivers. These studies will help to identify critical points like diagnosis or relapse at which distress among caregivers is likely to increase and as well as define critical time points for optimal coping interventions.

## 5. Conclusions

This study revealed that venting as a coping mechanism does influence caregiving satisfaction on the second dimension of the caregiving satisfaction scale. This study therefore has revealed the role coping plays in caregiving satisfaction among cancer caregivers. For future researches, it is important to find out why the other domains of coping do not affect caregiving satisfaction on the first and second dimension of the caregiving satisfaction scale.

The study recommends interventions to attend to caregivers' emotion regulation skills and ability to manage negative emotions in a healthy way. Additionally, Fresco *et al.* [35] suggest that there is need for Emotion Regulation Therapy (ERT) to address worry and cogitation in caregivers with anxiety, worry, intolerance and depressive symptomatology.

## Ethical Considerations

Approvals to conduct the study were obtained from the Research and Ethics Committee of Mbarara University of Science and Technology (MUST) reference; MUREC 1/7. Ethical clearance from the Uganda Cancer Institute Institutional Research Board was sought before the study began. Participants were treated with respect in terms of their individual autonomy, dignity, freedom of choice and human rights. They were asked to give voluntary verbal and written consent after which they were informed of their rights not to participate, and that if they chose to withdraw at any point, that would not affect their patient's care in any way. They were informed that a copy of research findings would be availed on request.

## Conflicts of Interest

Authors declare no conflicts of interest.

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