



# The other untold burden of cancer in sub-Saharan Africa: Anxiety and depressive symptoms among family caregivers of adult cancer patients

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## ABSTRACT

**Background:** Cancer incidence in sub-Saharan Africa (SSA) is increasing and family caregivers (FCGs) play a critical role in ensuring good patient outcomes. FCGs face enormous caregiving and social demands, and this leads to psychological and mental health problems, for which they receive no support or care.

**Objective:** To describe the extent of depression and anxiety symptoms among FCGs of adult cancer patients (ACPs) and the associated factors.

**Methods:** A descriptive cross-sectional design and standardized scales (hospital anxiety and depression scale, caregiver reaction scale, and Katz index) were used to assess anxiety and depressive symptoms, and impact of caregiving on the physical health of 284 FCGs of ACPs in Uganda.

**Results:** The majority of FCGs were caring for ACPs with stage 3 or 4 cancer (56%) and severe or very severe pain (73.1%). The prevalence of anxiety (35.2%) or severe anxiety (20%) and depression (48.2%) or severe depression (27.5%) symptoms were high. Anxiety was associated with self-rated health (OR [odds ratio] = 2.01;  $p = 0.013$ ) and impact of caregiving on physical health (OR = 2.04;  $p = 0.000$ ). Depression was associated with ACP pain (OR = 1.34;  $p = 0.030$ ), ACP functional status (OR = 0.61;  $p = 0.004$ ), time since cancer diagnosis (OR = 0.49;  $p = 0.010$ ), FCG self-rated health (OR = 2.24;  $p = 0.007$ ) and impact of caregiving on physical health (OR = 2.18;  $p = 0.000$ ).

**Conclusions:** The increasing incidence of cancer in SSA has led to high rates of poor mental health (anxiety and depression) among FCGs. Specific FCG and ACP factors can help us to identify FCGs at risk of depression and anxiety for early intervention.

## 1. Introduction

Approximately 57% of all the new cancer cases around the world occur in less developed countries (Torre, Siegel, Ward, & Jemal, 2016). The majority of less developed countries are in sub-Saharan Africa and are faced with a status of low healthcare system readiness and lack of adequate cancer care resources to cope with the healthcare needs of cancer patients (Magrath & Sutcliffe, 2014). Due to the cost of care and lack of the necessary resources, patients with cancer are increasingly staying in hospitals for shorter periods of time (Coriat et al., 2012), and more and more cancer treatment is taking place in outpatient settings (Vallerand, Collins-Bohler, Templin, & Hasenau, 2007). This change has put the family caregivers (FCGs) at the forefront of cancer care and they are increasingly playing key roles, and have multiple responsibilities once the cancer patient returns home.

The sudden nature in which the cancer diagnosis comes, the

uncertainty associated with the disease, and the associated caregiving burden, impacts the FCGs' psychological and emotional well-being. Various studies have showed that a large number of FCGs of cancer patients suffer from significant levels of anxiety and depression as a result of caregiving (Groß, Dahl, Moum, & Fosså, 2005). The caregivers of patients with advanced cancer are indeed more likely than individuals in the general population to have an initial major depressive episode and generalized anxiety disorders (Trevino, Prigerson, & Maciejewski, 2018). However until today, most of the studies about the psychological well-being and mental health of FCGs of cancer patients have been conducted in developed countries with advanced health care systems. Very few studies about the plight and health outcomes of FCGs of cancer patients have been conducted in resource limited settings or sub-Saharan Africa.

The few studies conducted in countries such as Uganda and South Africa, show that the primary stressors of FCGs of cancer patients are

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those related to the day-to-day patient care, emotional support, financial hardships and social isolation (Streid et al., 2014). A recent study reported that the FCGs of adult cancer patients (ACPs) in Uganda perform more extensive roles while caring for ACPs and these may include providing emotional support, giving medications, feeding the patient, and others, and they do these activities even when the patient is still hospitalized (Muliira, Kizza, & Nakitende, 2018). In addition to caregiving, the FCGs in sub-Saharan Africa (SSA) are more predisposed to simultaneously perform additional gender designated roles and income earning activities for the family together with the caregiving responsibilities (Githaiga, 2015). Therefore the stressors faced by FCGs caring for cancer patients in resource-limited settings such as SSA are compounded by socio-cultural complexities, and need to be studied further before developing interventions to address them (Githaiga, 2017).

The combination of ill-equipped healthcare facilities and lack of healthcare system readiness translates into high caregiving burden and poor health outcomes for both the FCGs and ACPs. One of the most significant health outcomes of FCGs stemming from caring for a cancer patient is the psychological and social burden (Akpan-Idiok & Anarodo, 2014). Available studies show that in settings such as Nigeria, the psychological (43.3%) and social (46.7%) burden severely impacts a large proportion of FCGs (Akpan-Idiok & Anarodo, 2014). In Uganda, the dimensions of caregiver burden that imposes the severest impact on FCGs of cancer patients include general strain, disappointment and isolation (Muliira et al., 2018). The severe psychological distress and mental health problems stemming from caregiving burden are many times never attended to by the healthcare system due to lack of readiness or resources, and this leaves the FCGs in state of poor health.

At the time of this study there were no specific services provided by the healthcare systems in Uganda to enhance the plight and well being of FCGs of ACPs. The main focus of all healthcare and other related services was the cancer patients. This is a major gap in the healthcare system which needs to be addressed with educational, health screening, respite care, and other interventions to promote the well-being of FCGs. A study of FCGs of cancer patients receiving in-patient and outpatient care at the Uganda Cancer Institute, showed that a large number were affected by anxiety (45%) and depression (26%) (Katende & Nakimera, 2017). Although the study quoted above did not adequately explore the correlates of depression and anxiety symptoms, and had a small sample (N = 119) recruited from a single cancer care centre in Uganda, it was the first to highlight the impact of caregiving on the mental health of FCGs of cancer patients in the country.

### 1.1. Purpose of the study

The current paper describes the extent of depression and anxiety symptoms among FCGs of ACPs and the associated modifiable factors. There are currently few risk assessment tools focusing on the mental health of FCGs of ACPs. The few that are available focus on bereavement risk assessment (Uchida, Satake, Nakaho, Inove, & Saito, 2018). We anticipate that characterizing the modifiable factors associated with anxiety and depression among FCGs of ACPs may stimulate development of appropriate risk assessment tools and clinical interventions to curtail these health outcomes.

## 2. Methods

### 2.1. Design

This was a descriptive cross-sectional survey of FCGs of ACPs. This design was the most appropriate since there were no adequate studies of the magnitude and correlates of depression and anxiety in FCGs of ACP in Uganda or other countries in SSA that could be used to guide the development of effective interventions. The survey was conducted between April and August of 2016 among FCGs of ACPs that were

receiving care at Hospice Africa Uganda (HAU) and the Uganda Cancer Institute (UCI). The survey was part of a larger study that developing and delivered a home-based intervention to enhance the well-being of FCGs and ACPs pain management (Kizza & Muliira, 2018).

### 2.2. Participants and setting

The participants were FCGs (spouse, child, relative, friend, or neighbour) and had to be the person who regularly provides homecare and assistance such as personal physical and psychosocial care, and other health-related care and support to the ACP receiving cancer care through the UCI and HAU. The UCI and HAU are the main providers of cancer care services (through in-patient units/wards, clinics and home care services) in the country and they receive referrals from different facilities in Uganda's healthcare system. The UCI is the only national and government facility dedicated to providing cancer treatment and care services in Uganda. The HAU is the main organisation that provides palliative care in Uganda through the district health units and home care programs (Merriman & Harding, 2010). The average annual case load of UCI is estimated at 2000 newly diagnosed cancer patients (Okuku et al., 2013) and HAU annually cares for an estimated 22,000 patients with life-limiting illness and 61% of these are confirmed terminal cancer cases (Hospice Africa Uganda, 2013).

The FCGs were recruited through the out-patient clinics, wards, and home-based care services of the UCI and HAU. The FCGs self-identified or were identified by the ACP as their primary caregiver. The inclusion criteria for the FCGs was: age of at least 18 years; ability to speak and read English (the official language) or Luganda (the commonly spoken local language); has been providing care for the ACP for at least four weeks; and living in the same household as the ACP. The FCG had to be providing care to an ACP of age 18 years and above and with a confirmed cancer diagnosis. The FCGs were excluded if they were caring for ACPs who were referred from other countries; they were individuals hired by the family to provide care; and if they had history of cancer, mental illness or a psychiatric disorder.

### 2.3. Study instrument

Data were collected using the Hospital Anxiety and Depression scale (Zigmond & Snaith, 1983), Caregiver Reaction Assessment scale (Given et al., 1992), and the Katz Index of Independence (KII) measure of patient functional status (Katz, Down, Cash, & Grotz, 1970). A forward-backward translation of the validated questionnaire was done by two independent language experts proficient in both English and Luganda. The questionnaire was then pre-tested among 10 FCGs. The Hospital Anxiety and Depression Scale (HADS) contain fourteen items and two subscales each with 7 items (Zigmond & Snaith, 1983). The HADS assesses for the presence and degree of anxiety and depressive symptoms as experienced over the past few weeks. The FCGs responded to each item on a four-point-Likert scale ranging from "0" to "3". The total subscale scores range from 0 to 21 with higher scores showing severe symptom levels. The cut-off scores ranges that represent normal status, borderline/probable cases of anxiety disorder or depression, and cases of mood disorder or disease are "0 to 7", "8 to 10", and "11 to 21", respectively (Zigmond & Snaith, 1983).

The psychometric properties of the HADS as a screening instrument for clinical anxiety and depression, shows that the scale is most specific and sensitive at a cut-off of total subscale score of 8.0 (Bjelland, Dahl, Haug, & Neckelmann, 2002). The HADS is a reliable and valid scale with subscale Cronbach's alpha ranging from 0.68 to 0.93 (mean = 0.83) for the anxiety subscale (HADS-A), and 0.67 to 0.90 (mean = 0.83) for the depression subscale (HADS-D) (Bjelland et al., 2002). The HADS is also highly reliable and valid when used for screening in FCGs of cancer patients (Gough & Hudson, 2009) and other populations (Jutte, Needham, Pfoh, & Bienvenu, 2015; Turk et al., 2015). The Cronbach's alphas in this study were 0.70, 0.75, and 0.83

for the HADS-A, HADS-D and the entire scale (HADS-T), respectively.

The Caregiver Reaction Assessment scale (CRA) has five subscales and the construct validity tests show that each subscale represents a specific construct and can be used independently (Given et al., 1992; Nijboer, Triemstra, Tempelaar, Sanderman, & van den Bos, 1999). The subscale which assesses the impact of caregiving on the physical health status of FCGs was used (5 items). The FCGs responded to the items on a 5-point likert scale; strongly agree (5 points) to strongly disagree (1 point). The sum was computed (ranges from 4 to 20) with higher scores indicating greater impact of caregiving on the FCGs' physical health. The Cronbach's alpha of the subscale in this study was 0.73. The FCGs also rated their health status as compared to how it was at the same time in the past one year using a single item-scale ranging from 1 to 10 (1 = being 'very healthy' and 10 = being 'very ill'). A score of 6 or higher showed poor health status.

The KII was used to assess the functional status of the ACPs cared for by the FCGs. The KII measures the extent to which individuals are able to independently perform the six activities of daily living (Katz et al., 1970). A score of "1" on each of the activity of daily living (ADL) implied independent performance while a score of "0" meant performance with assistance or complete inability to perform the activity. The total scores were interpreted as "6 = full function", "4 = moderate functional impairment", and " $\leq 2$  = severe functional impairment". The Cronbach's alpha of the KII in the current study was 0.86.

#### 2.4. Ethical considerations

The study was approved by the research and ethics committees of the UCI and HAU (REO/AC/02) as well as the Uganda National Council of Science and Technology (SS4003). The participants (FCGs) were adults and were required to read and sign a written informed consent form upon receipt of verbal and written explanation of the study purpose, procedures, rights and the confidentiality statement. The FCGs who were found to have severe levels of anxiety and depressive symptoms were advised and referred to seek care from the outpatient department's mental health clinic.

#### 2.5. Data collection procedure

The data was collected while the FCGs had escorted the ACPs to receive health care services (257 participants) or during home care visits (27 participants). The eligible FCGs were identified with the help of the ACP or nursing staff assigned to the ACP. Eligible FCGs were approached and asked to confirm if they are the primary caregiver for the identified patient. The ACPs were asked to identify their primary caregiver if more than one person provided care. The FCGs who were willing to participate in the study signed a consent form and a copy was given to them before initiating the data collection interview. Data was collected at a convenient time agreed upon with the FCGs. A total of 399 FCGs were found to be eligible and of these 284 (71.2%) participated in the study. The reasons for refusal by some FCGs included; critical condition of the ACPs (10%), lack of interest (6.3%), lack of another person to assist with ACP care needs (5%), and staying very far from the health care facility (7.5%).

#### 2.6. Statistical analysis

Data were analysed using the Statistical Packages for Social Sciences (SPSS) version 19 (SPSS Inc. Chicago, IL, USA). Descriptive statistics were used during univariate analysis. Preliminary analysis indicated that the HADS-A scores (Fisher's measure of skewness = 4.32, Kurtosis = -0.33) and HADS-D scores (Fisher's measure of skewness = 1.43, Kurtosis = -0.747) were skewed to the right. The optimal threshold for screening (score of 8) was then used as the cut-off point for both subscales (HADS-A and HADS-D) to categorise the scores as normal (score  $\leq 7$ ) and probable cases of emotional distress

**Table 1**  
Characteristics of the family caregivers (N = 284).

Characteristic	Category	N = 284 f (%)
Age in years (M = 36 $\pm$ 13.8)	18–30	137 (48.2)
	31–50	97 (34.2)
	$\geq 51$	50 (17.6)
Gender	Male	76 (26.8)
	Female	208 (73.2)
Marital status	Single/Widow/ Separated	113 (39.8)
	Married/Living with partner	171 (60.2)
	Spouse	57 (20.1)
Relationship with patient	Child	110 (38.7)
	Others	117 (41.2)
	Not employed	123 (43.3)
Employment status	Private Business	121 (42.6)
	Government/ company	40 (14.1)
	Highest level of education	$\leq$ Primary school
Length of time (months) spent as a family caregiver (M = 19.7 $\pm$ 27.9)	Secondary school	102 (35.9)
	Post-secondary	97 (34.2)
	7–11	135 (47.5)
Caregiving hours per week (M = 108 $\pm$ 55.2)	12–24	91 (32.1)
	$\geq 25$	58 (20.4)
	$\leq 48$	57 (20.1)
Self-rated health (M = 4.49 $\pm$ 2.57)	49–120	92 (32.4)
	$\geq 121$	135 (47.5)
	Good (1–5)	184 (64.8)
Impact of caregiving on physical health (M = 9.4 $\pm$ 3.36)	Poor ( $\geq 6$ )	100 (35.2)
	4–8	126 (44.4)
	9–13	121 (42.6)
Receives help with the caregiving role	14–18	37 (13)
	Yes	221 (77.8)
Receives support from an organisation	No	63 (22.2)
	Yes	79 (27.8)
FCG has a chronic illness	No	205 (72.2)
	Yes	73 (25.7)
	No	211 (74.3)

(scores  $\geq 8$ ). This led to a binary outcome for the variable of anxiety and depression symptoms. At bivariate analysis, Pearson's Chi-square ( $\chi^2$ ) was used to establish the factors associated with anxiety and depressive symptoms. Binary logistic regression analysis was performed using factors found to be significant at bivariate analysis to establish the predictors of clinically significant anxiety and depressive symptoms among FCGs. The Hosmer and Lemeshow goodness-of-fit test was used to determine whether the logistic model fitted well with the data in order to draw conclusions. In all analyses the level significance was set at  $\leq 0.05$ .

### 3. Results

#### 3.1. Characteristics of the family caregivers

The characteristics of the FCGs are summarized in Table 1. The majority of FCGs (58.8%) were either a spouse or a child of the ACP. The other FCGs (41.2%) reported their relationship to the ACP as sibling, mother, in-law, friend, grandchild, niece or neighbour. The majority of FCGs spent more than 121 h per week (47.5%) on caregiving responsibilities and only 27.8% received some kind of organizational support. The main reason for not receiving organizational support was having residences located outside the catchment area supporting organizations. Although the majority of the FCGs reported good health status (64.8%), a large number (55.6%) felt that caregiving had a high impact on their physical health. Some FCGs (25.7%) were engaged in caregiving responsibilities while having a chronic disease such as hypertension, diabetes mellitus, gastrointestinal ulcers, musculoskeletal pain, and HIV/AIDS.

**Table 2**  
Characteristics of the adult cancer patients (N = 284).

Characteristic	Response	N = 284 f (%)
Age in years (M = 50.2 ± 17.1)	18–30	44 (15.5)
	31–50	105 (37.0)
Gender	≥ 51	135 (47.5)
	Male	103 (36.3)
Highest level of education	Female	181 (63.7)
	≤ Primary school	143 (50.4)
	Secondary school	66 (23.2)
Cancer diagnosis	Post-secondary	75 (26.4)
	Breast cancer	52 (18.3)
	Cervical cancer	35 (12.3)
	Leukemia	35 (12.3)
Cancer stage	Colorectal cancer	20 (7.1)
	Others	142 (50)
	Stage 1	15 (5.3)
	Stage 2	58 (20.4)
	Stage 3 or 4	159 (56.0)
Period since cancer diagnosis in months (M = 19.2 ± 28.9)	Cannot be staged	52 (18.3)
	1–12	166 (58.5)
	13–60	102 (35.9)
Patient's functional status (M = 4.49 ± 2)	≥ 61	16 (5.6)
	≤ 2 (severe)	70 (24.6)
	3–5 (moderate)	55 (19.4)
Patient's pain rating	6 (Fully functional)	159 (56.0)
	≤ 3 (mild)	13 (4.6)
	4–6 (moderate)	63 (22.3)
	7–8 (severe)	89 (31.2)
Patient's period of pain in months (M = 21.4 ± 37.8)	9–10 (very severe)	119 (41.9)
	1–12	164 (57.7)
	13–60	98 (34.5)
Ranking of the most disturbing symptoms (multiple responses)	≥ 61	22 (7.8)
	Pain	210 (73.9)
	No appetite/general weakness	46 (16.2)
	Nausea/lack of sleep	19 (6.7)
	Feeling tired of hospital	24 (8.5)

3.2. Characteristics of the adult cancer patients (ACPs)

Table 2 presents the characteristics of ACPs who were being cared for by the FCGs. Most of the ACPs were diagnosed with cancer of the breast (18.3%), cervix (12.3%), and leukaemia (12.3%). The other notable cancer diagnoses were cancers of oesophagus, prostate, ovary, pancreas, stomach, Lymphomas, and multiple myeloma. A large number of ACPs had cancer at stage 3 or 4 (56%) and were receiving chemotherapy (66.9%). The other types of treatment the ACPs were receiving were radiotherapy (3.5%), surgery (3.2%) or no active treatment (26.4%). The ACPs had moderate functional status impairment (mean = 4.49, SD = 1.9) with only 24.6% having severe functional status impairment. On average the ACPs experienced 4.5 ± 2 symptoms and the most disturbing symptom was pain. The majority of ACPs reported having on and off pain (66.2%).

3.3. Prevalence of anxiety and depressive symptoms among the FCGs of ACPs

Table 3 shows the distribution of FCGs by the level of anxiety and depressive symptoms. Based on the optimal screening threshold for the HADS-A and HADS-D subscales (score ≥ 8), 35.2% of the FCGs had clinically significant symptoms of anxiety and 48.2% had clinically significant symptoms of depression. Of the 284 FCGs included in the study, 20% experienced severe symptoms of anxiety and 27.5% experienced severe symptoms of depression.

**Table 3**  
Assessment of participants' anxiety and depression using HADS (N = 284).

Descriptive Category	Anxiety (HADS-A)	Depression (HADS-D)
FCGs with scores above threshold (score ≥ 8)	35.2%	48.2%
FCGs within normal limits (score = 0–7)	64.8%	51.8%
FCGs who are borderline (score = 8–9)	15.1%	20.8%
FCGs with mood disorder or disease (score = 11–21)	20.1%	27.5%
Mean (Standard Deviation)	6.3 (4.5)	7.4 (4.5)
Fisher's measure of skewness	4.32	1.43
Skewness (Standard error)	0.627 (0.145)	0.207 (0.145)
Fisher's measure of kurtosis (Standard error)	-0.330 (0.288)	-0.747 (0.288)

3.4. Modifiable factors associated with FCGs level of anxiety symptoms

Table 4 summarises the factors associated with FCGs' anxiety symptoms. A total of 184 (64.8%) FCGs had symptoms which were within normal limits and 100 (35.2%) had scores showing possible anxiety. The FCGs who perceived a high impact of caregiving role on their physical health ( $\chi^2 = 24.45$ ;  $p = 0.000$ ); poor self-reported general health ( $\chi^2 = 16.87$ ;  $p = 0.000$ ), and who cared for functionally impaired ACPs ( $\chi^2 = 13.98$ ;  $p = 0.001$ ) had clinically significant symptoms of anxiety in significantly higher proportions. The other FCG and ACP factors were not statistically significantly associated with the level of anxiety symptoms.

3.5. Modifiable factors associated with FCGs' level of depressive symptoms

The results in Table 5 show the factors associated with FCGs' level of depressive symptoms. A total of 147 (51.8%) FCGs had symptoms which were within normal limits and 137 (48.2%) had scores showing possible depression. The FCGs who perceived a severe impact of caregiving on physical health ( $\chi^2 = 31.71$ ,  $p = 0.000$ ); poor self-rated health ( $\chi^2 = 19.50$ ;  $p = 0.000$ ); ACPs with impaired functional status ( $\chi^2 = 21.00$ ;  $p = 0.000$ ) and severe pain levels ( $\chi^2 = 14.35$ ;  $p = 0.000$ ), had clinical significant depressive symptoms in significantly higher proportions. The other FCG and ACP factors were not statistically significantly associated with the level of depressive symptoms.

3.6. Predictors of anxiety and depressive symptoms in FCGs of adult cancer patients

The results of the logistic regression analysis are presented in Table 6. The Hosmer and Lemeshow Goodness-of-fit test results for the FCGs' scores on the HADS-A [ $\chi^2 (7, n = 284) = 5.63, p = 0.583$ ] and HADS-D [ $\chi^2 (8, n = 284) = 5.46, p = 0.708$ ] showed that the models predicted values were not significantly ( $p > 0.05$ ) different from the observed values. The results show that FCG self-rated health (OR = 2.01, CI = 1.161–3.488) and perceived impact of caregiving on their physical health (OR = 2.04, CI = 1.372–3.033), significantly predicted anxiety symptoms in FCGs. FCGs who rated their health as poor were two times more likely to report severe symptoms of anxiety compared to those with good self-rated health. Similarly, FCGs who perceived a high impact of caregiving on their physical health were two times more likely to have clinically significant anxiety compared to those who perceived a low impact.

The significant predictors of clinical significant depressive symptoms were; time since confirmation of ACP cancer diagnosis (OR = 0.49, CI = 0.29–0.85), ACP's level of pain (OR = 1.34, CI = 1.03–1.75), ACP's functional status (OR = 0.61, CI = 0.44–0.85), self-rated health status (OR = 2.24, CI = 1.25–4.00) and perceived impact of caregiving on physical health (OR = 2.18, CI = 1.43–3.323).

**Table 4**  
Factors associated with FCGs' anxiety symptoms (N = 284).

Factor	Response	N = 284 f (%)	Anxiety (HADS-A)		Chi-square ( $\chi^2$ ) and p-value (p)	
			Score $\leq$ 7 (n = 184) f (%)	Score $\geq$ 8 (n = 100) f (%)		
Family Caregiver (FCG)	Gender	Male	76 (26.8)	58 (31.5)	18 (18)	$\chi^2 = 6.04$
		Female	208 (73.2)	126 (68.5)	82 (82)	p = 0.014
	Perceived impact of caregiving on physical health	4-8	126 (44.4)	100 (54.3)	26 (26)	$\chi^2 = 24.45$
		9-13	121 (42.6)	69 (37.5)	52 (52)	p = 0.000
		14-18	37 (13)	15 (8.2)	22 (22)	
	Self-rated health	Good ( $\leq$ 5)	184 (64.8)	135 (73.4)	49 (49)	$\chi^2 = 16.87$
Poor ( $\geq$ 6)		100 (35.2)	49 (26.6)	51 (51)	p = 0.000	
Caregiving hours per week	$\leq$ 120	149 (52.5)	95 (51.6)	54 (54)	$\chi^2 = 0.15$	
	> 120	135 (47.5)	89 (48.4)	46 (46)	p = 0.703	
Adult Cancer Patient (ACP)	Functional status	$\leq$ 2	70 (24.6)	41 (22.3)	29 (29)	$\chi^2 = 13.98$
		3-5	55 (19.4)	26 (14.1)	29 (29)	p = 0.001
		6	159 (56)	117 (63.6)	42 (42)	
	Period of pain (months)	$\leq$ 12	164 (57.7)	108 (58.7)	56 (56)	$\chi^2 = 0.19$
		> 12	120 (42.3)	76 (41.3)	44 (44)	p = 0.660
	Pain rating (0-10)	Moderate ( $\leq$ 6)	145 (51.1)	99 (58.7)	46 (46)	$\chi^2 = 1.58$
		Severe ( $\geq$ 7)	139 (48.9)	85 (41.3)	54 (54)	p = 0.209

The likelihood of reporting clinically significant depressive symptoms among FCGs who perceived a high impact of caregiving on physical health and poor health status was twice that of the FCGs who perceived a lower impact and good health status. The FCGs who cared for ACPs with severe pain were 1.3 times more likely to report clinically significant depressive symptoms. For every 1 point decline in the ACP's functional status, the odds of clinically significant depressive symptoms increased by 0.61. For every 1 point decrease in the period since cancer diagnosis, the odds of experiencing clinically significant depressive symptoms increased by 0.40.

The Wald statistic was used to evaluate whether or not the logistic coefficient (B) for each of the predictors was different from zero. Therefore, FCGs' self-rated health (p < 0.01) and perceived impact of caregiving on physical health (p < 0.01) contributed significantly to the prediction of clinically significant levels of anxiety and depressive symptoms. The Wald statistics also indicates that the ACP pain level (p < 0.05), ACP functional status (p < 0.01), and period since

receiving a confirmed cancer diagnosis (P = 0.01) contributed significantly to the prediction of clinically significant depressive symptoms.

#### 4. Discussion

In resource-limited settings, the FCGs of cancer patients hold a unique position in the cancer care delivery system because they provide care and bare intense care demands in both the hospital and home settings, and this leads them to suffer severe psychological and emotional distress. In resource limited settings, the FCGs help to ensure continuity of care while the ACP is admitted in the hospital or at home. Our study found that FCGs caring for ACPs suffer from a high level of clinically significant anxiety (35.2%) and depression symptoms (48.2%). This shows that FCGs are an asset to the cancer care services, but they are also individuals who struggle with helplessness (Ekstedt, Stenberg, Olsson, & Ruland, 2014).

**Table 5**  
Factors associated with FCGs' Depressive symptoms (N = 284).

Factor	Response	N = 284 f (%)	Depression (HADS-D)		Chi-square ( $\chi^2$ ) and p-value (p)	
			Score $\leq$ 7 (n = 147) f (%)	Score $\geq$ 8 (n = 137) f (%)		
Family Caregiver (FCG)	Age in years	18-30	137 (48.2)	80 (54.4)	57 (41.6)	$\chi^2 = 5.05$
		31-50	97 (34.2)	46 (31.3)	51 (37.2)	p = 0.08
		$\geq$ 51	50 (17.6)	21 (14.3)	29 (21.2)	
	Level of educational	$\leq$ Primary	85 (29.9)	37 (25.2)	48 (35)	$\chi^2 = 6.57$
		Secondary	102 (35.9)	50 (34)	52 (38)	p = 0.037
		Post-secondary	97 (34.2)	60 (40.8)	37 (27)	
	Perceived impact of caregiving on physical health	4-8	126 (44.4)	88 (59.9)	38 (27.7)	$\chi^2 = 31.71$
		9-13	121 (42.6)	49 (33.3)	72 (52.6)	p = 0.000
		14-18	37 (13)	10 (6.8)	27 (19.7)	
	Self-rated health	Good ( $\leq$ 5)	184 (64.8)	113 (76.9)	71 (51.8)	$\chi^2 = 19.50$
Poor ( $\geq$ 6)		100 (35.2)	34 (23.1)	66 (48.2)	p = 0.000	
Caregiving hours per week	$\leq$ 120	149 (52.5)	83 (56.5)	66 (48.2)	$\chi^2 = 1.95$	
	> 120	135 (47.5)	64 (43.5)	71 (51.8)	p = 0.162	
Adult Cancer Patient (ACP)	Period since cancer diagnosis (months)	$\leq$ 60	166 (58.5)	76 (51.7)	90 (65.7)	$\chi^2 = 5.72$
		$\geq$ 61	118 (41.5)	71 (48.3)	47 (34.3)	p = 0.017
	Functional status	$\leq$ 2	70 (24.6)	23 (15.7)	47 (34.3)	$\chi^2 = 21.00$
		3-5	55 (19.4)	23 (15.7)	32 (27.8)	p = 0.000
		6	159 (56)	101 (68.7)	58 (42.3)	
	Pain rating (0-10)	Moderate ( $\leq$ 6)	145 (51.1)	91 (61.9)	54 (39.4)	$\chi^2 = 14.35$
		Severe ( $\geq$ 7)	139 (48.9)	56 (38.1)	83 (60.6)	p = 0.000

**Table 6**  
Predictors of FCGs' degree of anxiety and depression (N = 284).

Outcome	Factor	B (logistic coefficient)	Wald	p-value	Exp (B) (odds ratio)	95% CI
<i>Anxiety (HADS-A)</i>	FCG's gender	0.58	3.16	0.075	1.78	0.94–3.36
	FCG's self – rated health	0.70	6.21	0.013	2.01	1.16–3.49
	FCG's perceived impact of caregiving on physical health	0.71	12.42	0.000	2.04	1.37–3.03
	Patient's functional status	– 0.28	3.07	0.080	0.76	0.56–1.03
<i>Depression (HADS-D)</i>	FCGs' level of education	– 0.09	0.26	0.613	0.92	0.65–1.29
	FCG age in years	0.18	0.41	0.521	1.20	0.69–2.09
	FCG's perceived impact of caregiving on physical health	0.78	13.00	0.000	2.18	1.43–3.33
	FCG's self – rated health	0.81	7.39	0.007	2.24	1.25–4.00
	Period since cancer diagnosis	– 0.71	6.57	0.010	0.49	0.29–0.85
	Patient's functional status	– 0.49	8.47	0.004	0.61	0.44–0.85
	Patient's pain level	0.29	4.58	0.032	1.34	1.03–1.75

An earlier study conducted among FCGs in a single cancer centre in Uganda reported the prevalence of anxiety to be higher (45%) and that of depression to be lower (26%) (Katende & Nakimera, 2017). Although there is no exact match in the prevalence rates of anxiety and depression, the overall highlight of our study and that of Katende and Nakimera (2017) is the high level of anxiety and depression among FCG of cancer patients. Due to the lack of studies about FCGs of cancer patients in developing countries and other resource limited settings, the available reference points are mostly studies conducted in developed countries. For instance the rate of severe anxiety (20%) and severe depression (27.5%) reported by our study are much higher than what has been reported by studies from developed countries. The prevalence of anxiety among FCGs of cancer patients in South Korea has been reported as 38.1% (mild = 20.3%, moderate = 13.3%, and severe = 4.6%) and the rate of depression was 82.2% (mild = 40.4%, moderate = 25.5%, and severe = 16.3%) (Park, Kim, Shin, Sanson-Fisher, Shin, Cho, & Park, 2013).

A study conducted in the Boston (Massachusetts) area of USA showed that FCGs reported anxiety at a rate of 42.2% and depression at 16.4% (Nipp et al., 2016). In UK, a study conducted among FCG of head and neck cancer patients found that 34% had depression and 25% had anxiety (Balfe et al., 2018). It seems that FCGs of ACPs within resource-limited settings tend to suffer from severe anxiety and depressive symptoms in high proportions compared to their counterparts in developed countries with well-established cancer care services and healthcare systems. This leads us to suggest that one of the under reported outcomes of the increasing burden of cancer in resource-limited settings such as Uganda and other Sub-Saharan Africa countries, is the mental health burden associated with the caregiving responsibilities.

Other studies of FCGs of cancer patients have reported that depression is significantly associated with feeling uncomfortable with caregiving tasks, female gender, and being a spouse to the patient, while anxiety is associated with feeling uncomfortable with caregiving tasks, having financial stress and a recent cancer diagnosis (Balfe et al., 2018). In our study depressive symptoms were associated with time since confirmation of ACP cancer diagnosis, ACP's level of pain, ACP's functional status, FCG self-rated health status and perceived impact of caregiving on physical health. The anxiety symptoms were significantly associated with FCG self-rated health and perceived impact of caregiving on their physical health. Previous studies have found that being involved in psychological issues of the patient, young age, not being a spouse, and having no previous experience in caring for a patient with cancer negatively influence the quality of life of the FCG (Effendy et al., 2015).

The above discussion shows that the FCGs' and cancer patients' physical and mental health are correlated and affect one another's' mental and physical health. Therefore the FCG and ACPs physical and mental health are interdependent (Kershaw et al., 2015). This highlights the importance of efforts to maintain the health and well-being of FCGs. Efforts should be made by providers of cancer care services to

provide care that addresses the needs of the dyad (ACPs and FCGs). This approach to cancer care is most likely to reduced care costs as a result of good health outcomes for both the ACP and FCG.

In resource limited settings FCGs are more likely to be helpless when it comes to their health care needs. Even in settings with well-established health care systems such as Norway, the FCGs of cancer patients are perceived by the health care professionals as individuals who struggle with helplessness (Ekstedt et al., 2014). Therefore as the number of FCG for ACPs continues to increase due to the upward trend of cancer incidence in developing countries and other resource limited settings, there is need for more emphasis on the provision of support and health care for FCGs. Support and health care for FCGs enables them to optimally care for ACPs and reduces morbidity of both FCGs and ACPs.

The caregiving role and the various challenges involved elicit psychological distress and mental health problems. Our study offers new data from a resource limited setting to support deliberate support and health care interventions to meet the health and health promotion needs of FCGs of ACPs. This way the FCGs are not only viewed as a principle source of support for the ACPs, but also as client who need supportive care. Cancer care services which balance between the needs of the ACP and their FCG are needed and are the only viable future since they ensure good holistic outcomes for the patient and the family. We recommend further prospective research into caregiver burden and mental health of FCGs of ACP in resource-limited settings using longitudinal methods to investigate the changes in physical and mental health status, coping, and caregiving demands during the different disease trajectories.

#### 4.1. Limitations

The results of our study should be considered in view of its limitations such as the use of a cross-sectional design (limits understanding of trends and changes associated with time or change in patient's condition), convenience sample, and inability to objectively assess the ACPs health status beyond the functional status. The anxiety and depressive symptoms were assessed using self-report method and this can never be equivalent to a well-structured clinical assessment and diagnosis. The FCGs were also taking care of ACPs with different cancer diagnoses and at different stages of the disease trajectory. Some cancers may progress quickly (lead to death quite quickly) or elicit more severe symptoms and functional impairments compared to others. Thus cohort studies for specific cancer diagnoses and longitudinal studies are better placed to give a clear understanding of the ACP changes and FCG factors that can predict psychological distress and mental health outcomes of the FCGs.

## 5. Conclusion

Family caregivers of ACPs experience high levels of anxiety and depression symptoms and this part due to care giving burden, the lack

of support for FCGs, and lack of health care system readiness to provide holistic cancer care services in resource-limited settings. This study has showed that specific FCG and ACP factors such as physical health, self-rated health, ACP pain and functional status are associated with clinically significant anxiety and depression. The associated factors need to be studied further to develop accurate risk prediction models to identify FCG at a very high risk and target them early with preventive interventions. The associated factors also provide us with insights about the needed interventions to address the emerging mental health burden among FCGs of ACPs.

### Authors' contribution

JKM initiated the conception of the study and participated in data collection, data analysis and writing for the final manuscript. IBK participated in data collection, data analysis and writing of the manuscript. All authors read and approved the final draft of the manuscript.

### Ethical approval

Ethical clearance was obtained from the research and ethics committees of the Uganda Cancer Institute and Hospice Africa Uganda (REO/AC/02) as well as the Uganda National Council of Science and Technology (SS4003). Written informed consent was obtained from all participants.

### Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

### Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.ijans.2019.100166>.

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