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ORIGINAL ARTICLE

Family caregivers for adult cancer patients: knowledge and self-efficacy for pain management in a resource-limited setting

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Abstract Adult cancer patients (ACPs) in resource-limited settings disproportionately suffer from inadequate pain control despite advancements in pain management. Family caregivers (FCGs) can support optimal pain control for ACPs in these settings if they are knowledgeable and confident about the needed care. However, the status of FCGs' knowledge and self-efficacy (SE) for pain management in developing countries is not well established.
Purpose To assess the FCGs' knowledge and SE levels for pain management among ACPs while at home in a resource-limited setting.
Methods Using a questionnaire that comprised a Family Pain Questionnaire and Chronic Pain Self-efficacy Scale, data were collected from 284 FCGs of ACPs receiving care from two cancer care centres.
Results The FCGs had moderate knowledge (mean = 41.70 ± 14.1) and SE (mean = 795.95 ± 301.3) levels for pain management at home for ACPs. Majority of the FCGs had low knowledge (52.1%), but expressed higher SE (52.5%). Poor self-rated health among FCGs was significantly associated with low knowledge levels (OR = 1.75; 95% CI 1.024–2.978, $p = 0.041$). SE was significantly associated with perceiving a low impact of caregiving on health (OR = 1.55; 95% CI 1.074–2.239, $p = 0.019$), hours of caregiving per week (OR = 0.52; 95% CI 0.315–0.854; $p = 0.01$) and receiving organisational support (OR = 0.388; 95% CI 0.222–0.679; $p = 0.001$).
Conclusion The results show a need for deliberate interventions to enhance FCG knowledge and SE for pain management at home as one of the ways of improving cancer pain management in resource-limited settings.

Keywords Family caregiver · Knowledge · Self-efficacy · Pain management · Cancer pain · Resource-limited

Introduction

The cancer disease trajectory is characterised by a high symptom burden (fatigue, pain, drowsiness, nausea and others). Of these symptoms, pain is highly ranked as a source of distress by adult cancer patients (ACPs) and their families [1, 2]. The majority (90%) of ACPs can achieve optimal pain relief given the scientific advancements on knowledge, management strategies and clinical practice guidelines [3, 4]. Disproportionately, a large number (21–84%) of ACPs still suffer intense uncontrolled pain during the disease course: at advanced disease stage (53–100%), on active anti-cancer treatment (44–73%) and those declared as cured of cancer (21–46%) regardless of cancer type [3, 5].

In resource-limited settings, 30 to 70% of ACPs experience moderate or severe pain [6]. In countries such as Uganda, ACPs express a huge symptom burden and pain is reported as the most prevalent (87%) and severely distressing symptom [7]. The portrayed pain-related burden depicts a serious mismatch between knowledge advancement and pain management [8, 9].

Several factors limit the attainment of optimal cancer pain control [10]. In resource-limited settings, healthcare system-related factors such as poor communication, limited access to

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drugs, and lack of family caregivers (FCGs) to support ACPs curtail continuity and quality pain management at home [11, 12]. The latter is a major limitation because according to the American Pain Society (APS) and the American National Comprehensive Cancer Network (NCCN), active involvement of the ACP and their family in pain management is tenant for quality pain management [13, 14]. This holistic approach maximises individualised care, comfort and improves ACP quality of life by addressing the cognitive, emotional and social aspects of the pain experience [8].

In view of the APS and NCCN recommendations, the health care systems in resource-limited settings, where human resource for cancer care is lacking, need to embrace the strategy of involving and ensuring the input of ACPs and their FCGs [15]. At home, the FCGs assume the tasks of monitoring the ACP's pain, applying non-drug pain control methods, administering prescribed pain medications and checking patient's response to interventions. The FCGs also manage medication side effects and give feedback about the ACPs' pain experience to the health care providers (HCPs) especially when ACPs cannot [16, 17]. Given the contribution level, FCGs should have appropriate attitude, cognitive and psychomotor skills.

In literature, the reports of worry about medication side effects, addiction and tolerance, beliefs of the inevitable nature of cancer pain and the perception of intensifying pain as a sign of cancer progression or impending death among FCGs of ACPs exist [10]. Pain management at home is highly ranked among the most challenging tasks due to FCGs' deficits in knowledge, skills, decision-making self-efficacy and experience [18–21]. Indeed, FCGs report feelings of helplessness, frustration and exhaustion, and wishing for death upon witnessing their ACPs in persistent pain or being unable to help the patient attain adequate pain control [17]. Literature shows that the FCGs' knowledge gaps about pain management are rooted in the lack of preparation and the unsupportive nature of the healthcare system [18]. In resource-limited settings such as Uganda, cancer care for ACPs depends a lot on the FCGs [15], but no study has explored their knowledge and SE for pain management at home. This study aimed to assess the level of knowledge and SE for pain management at home among FCGs of ACPs living in a resource-limited setting (Uganda).

Methods

A descriptive cross-sectional survey was conducted from May 2016 until June 2016 among 284 FCGs of ACPs.

Study participants and setting

The participants were FCGs of ACPs receiving cancer care at the Hospice Africa Uganda (HAU) and Uganda Cancer Institute (UCI). FCGs are the relatives, spouses, friends or neighbours who regularly provided assistance with pain management, activities of daily living, medical appointments and others to ACPs while at home and in hospital. The UCI, a government-funded facility, provides cancer treatment and receives 2000 newly diagnosed cancer patients annually [22]. HAU is the main organisation that provides palliative care in Uganda and receives an annual average of 22,000 patients with life-limiting illness, with the majority (61%) having confirmed cancer disease [23]. The UCI and HAU were purposively selected given their referral status.

The FCGs were recruited through out-patient clinics, wards and home-based care services. The FCGs identified themselves or by the ACP as the primary providers of assistance while in the hospital and at home. The FCG had to be: 18 years old or more, able to speak grade four English (the official language) or Luganda (the commonly spoken local language) and living in the same household with ACP; providing care to an ACP (at least 18 years old) with a confirmed cancer diagnosis and pain experience for at least 1 month. The FCGs were excluded if they were hired individuals or had a history of cancer.

Study instrument

Data were collected using an interviewer-administered questionnaire (IAQ) composed of the Family Pain Questionnaire (FPQ) [24], the Chronic Pain Self- efficacy Scale (CPSS) [25], the Caregiver Reaction Assessment subscale (CRA) [26] and the Katz Index of Independence scale [27]. The IAQ also had a section on FCGs' demographic information and patient characteristics. Three cancer pain management experts provided feedback on the adequacy, relevancy, appropriateness and clarity of the content as well as the extent to which the scales reflected the constructs of knowledge and SE for cancer pain management in Uganda [28]. The item and scale-level content validity indices of at least 0.93 were obtained. The IAQ was pre-tested among 10 FCGs of ACPs. Permission to use and make changes was obtained from the authors.

The FPQ measures FCGs' cancer pain management knowledge (9 items) and experience (7 items) [29] based responses on a 10-point scale with "0" as the most positive outcome and "10" as the most negative outcome. The revision of one item "pain medicines can be dangerous and often interfere with the breathing of the cancer patient" resulted in a total of 10 items on the knowledge subscale. A total knowledge score (ranging from 0 to 100) was computed for each participant, with low scores indicating high knowledge level. The Cronbach's alpha was 0.52 and 0.72 for the knowledge and experience subscales, respectively.

The modified version of the CPSS (16 items) was used to assess the FCGs' beliefs about their self-efficacy (SE) to support the ACP in pain management [25]. FCGs rated their perceived ability on a 10-point Likert scale (10 = "very uncertain" and 100 = "very certain"). The total SE score (160 to 1600) was obtained with high scores indicating high SE in cancer pain management. Similar to earlier studies [30, 31], the Cronbach's alpha in the current study was 0.94.

The CRA has five subscales (each subscale representing a specific construct) which can be used independently [26]. The caregiving impact on health status sub-scale (4-items) was used to assess the impact of caregiving on FCG physical health status [26]. FCGs' total scores were computed using their responses on a 5-point likert scale ("strongly agree" = 5 to "strongly disagree" = 1), with high scores showing greater impact on health. The Cronbach's alpha of the subscale in the current study was 0.73. FCGs also rated their health status on a single item-scale of 1 to 10 ("very healthy" = 1 to "very ill" = 10). A score of 6 or more showed distressed health status. The Katz index was used to assess the functional status of the ACPs cared for by the FCGs [27], where score "1" = independent performance and "0" = total inability or performance with assistance. A total score of "6" = full function, 4 = moderate function and ≤ 2 as severe functional impairment. The Cronbach's alpha of the Katz index in the current study was 0.86.

Procedure

The study was approved by HAU, UCI (REO/AC/02) and the Uganda National Council of Science and Technology (SS4003). The participants provided written informed consent. The IAQs were coded and no identifying information was recorded. Data were collected at the FCGs' conveniently selected time to ensure continued patient care.

On the data collection days, with the help of the nursing staff, the identified eligible FCGs were approached and asked to confirm if they were the FCGs for ACPs receiving care from HAU and UCI. The ACPs also helped to confirm the primary caregiver if more than one person provided care. The study purpose and participation level were explained to eligible FCGs and those who were willing to participate signed a consent form and a copy was given to them. Data were collected within the facility and home settings as agreed upon with the FCGs. The trained research assistants (RAs) recorded a FCG's responses to the questions during 75-min interview on average. A total of 399 FCGs were approached and of these 284 participated in the study. FCGs declined participation due to: the ACPs' critical condition, lack of interest, lack of help with patient care and living far from the hospital.

Statistical analysis

Data were analysed using Statistical Packages for Social Sciences (SPSS) version 19 (SPSS Inc. Chicago, IL, USA). Descriptive statistics were used during univariate analysis. Preliminary analysis indicated that FCGs' knowledge (Fisher's measure of skewness = 0.17, kurtosis = − 0.366) and SE (Fisher's measure of skewness = 0.23, kurtosis = − 0.614) scores were normally distributed. The mean scores and standard deviations summarised the knowledge and SE levels. Using the means as the cut-off, the knowledge (low knowledge level ≥ 42.00 and high knowledge ≤ 41.00) and SE scores (low SE < 795.00 and high SE ≥ 795.00) were categorised into binary outcomes. Pearson's Chi-square (x^2) statistic was used to examine the relationship between knowledge or SE and FCG and ACP characteristics. Binary logistic regression analysis was used to determine how relevant factors affected the probability of FCGs' knowledge and SE. The Hosmer and Lemeshow goodness-of-fit test was used to determine whether the logistic model fitted well with the data. For all analyses, significance level was set at ≤ 0.05.

Results

Characteristics of the participants

As shown in Table 1, the FCGs were relatively young (mean age = 36 years, SD = 13.8). The majority of FCGs were female (73.2%), partnered (60.2%), spent more than 120 h a week (47.5%) on caregiving and were responsible for two more adults (74%). The FCGs received help with caregiving mostly from relatives (77.8%) and only 27.8% received support from an organisation/agency (91.1% of the support was from HAU). The FCGs perceived a good health level (mean = 4.49, SD = 2.57) and rated the impact of the caregiving on their physical health as moderate (mean = 9.4, SD = 3.36). FCGs had chronic illnesses (25.7%) like hypertension, diabetes mellitus, gastrointestinal ulcers and musculoskeletal pain.

Characteristics of the ACPs cared for by the FCGs

In Table 2, results show that ACPs were mostly middle aged (mean = 50.2, SD = 17.1 years) females (63.7%) commonly diagnosed with breast (18.3%) and cervix (12.3%) cancers, leukaemia (12.3%) and colorectal (7.1%) cancer at disease stage 3 or 4 (56%). Most of the ACPs were receiving treatment in the form of chemotherapy (66.9%) and had moderately impaired functional status (mean = 4.49, SD = 1.9). The ACPs experienced an average of 4.5 (SD = 2) symptoms and the majority ranked pain as the first and most disturbing symptom (73.9%). Averagely, the ACPs had experienced pain for more than a year (mean = 21.4 months, SD = 3.8). The majority of ACPs reported having severe (31.2%) or very severe (41.9%) pain that was mostly "on and off" (66.2%). ACPs were on pain medication (92.3%), with oral morphine, ibuprofen and diclofenac as the commonly used analgesics and reported some extent pain relief (87%).

Table 1 Characteristics of the family caregivers

Characteristic of the caregiver	Response	($n = 284$) Frequency (%)
Age in years (M = 36, SD = 13.8)	18–30	137(48.2)
	31–50	97(34.2)
	≥ 51	50(17.6)
Gender	Male	76(26.8)
	Female	208(73.2)
Marital status	Single/widow/separated	113(39.8)
	Married or living with partner	171(60.2)
Relationship with patient	Spouse	57(20.1)
	Child	110(38.7)
	Other[a]	117(41.2)
Employment status	Not employed	123(43.3)
	Private business	121(42.6)
	Government/company	40(14.1)
Highest level of education	≤ primary school	85(29.9)
	Secondary school	102(35.9)
	Post-secondary	97(34.2)
Length of time as FCG (in months) (M = 19.7, SD = 2.79)	7–11	135(47.5)
	12–24	91(32.1)
	≥ 25	58(20.4)
Caregiving hours per week (M = 108, SD = 55.2)	≤ 48	57(20.1)
	49–120	92(32.4)
	≥ 121	135(47.5)
Impact on physical health (M = 9.4, SD = 3.36)	4–8	126(44.4)
	9–13	121(42.6)
	14–18	37(13)
Self-rated health (M = 4.49, SD = 2.57)	Good (1–5)	184(64.8)
	Poor/bad (≥ 6)	100(35.2)
Receives help with the caregiving role	Yes	221(77.8)
Receives support from an organisation	Yes	79(27.8)
Having a chronic illness	Yes	73(25.7)

[a] Includes sibling, mother, in-law, friend, grandchild, niece and neighbour

M mean, *SD* standard deviation

Participants' experiences with pain in cancer patients

As shown in Table 3, most of the FCGs felt that ACPs experienced severe pain in the week prior to the interview (66.2%), moderate to no pain relief (76.2%) and perceived great suffering to ACPs (79.2%) and themselves (83.7%) due to ACPs' pain. The FCGs perceived moderate ability to control ACPs' pain (mean = 5.39, SD = 2.9) with 33.8% expressing little or no ability at all. The FCGs (65.5%) did not apply non-drug methods because of not knowing what to do (75.3%), thinking of no need when the ACP is on pain killers (15%) and believing that other methods cannot relieve pain (2.7%). Only 34.5% of the FCGs used non-drug methods to control pain including massage (36.7%), applying heat (27.6%), comforting by reassuring (14.3%), applying cold (11.2%) and distraction with conversation, television or prayer (8.2%).

Participants' level of knowledge and self-efficacy for pain management

The results in Table 4 show the that FCGs' mean knowledge score was 41.7 (SD = 14.05) with the majority (52.1%) having low knowledge level. The FCGs were mostly knowledgeable about the need for the ACP to take pain medication "around the clock" (89.9%). Only 13.7% of the FCGs adequately understood that worsening pain level does not mean worsening cancer disease. The FCGs' mean score for SE was 795.95 (SD = 301.3), indicating moderate SE for pain management, with 47.5% perceiving low SE.

Table 2 Characteristics of the adult cancer patients

Characteristic	Response	$N = 284$ Frequency (%)
Age in years (M = 50.2; SD = 17.1)	18–30	44(15.5)
	31–50	105(37.0)
	≥ 51	135(47.5)
Gender	Male	103(36.3)
	Female	181(63.7)
Highest level of education	≤ Primary school	143(50.4)
	Secondary school	66(23.4)
	Post-secondary	75(26.4)
Cancer stage	Stage 1	15(5.3)
	Stage 2	58(20.4)
	Stage 3 or 4	159(56.0)
	Cannot be staged	52(18.3)
Duration since cancer diagnosis (in months) (M = 19.2; SD = 2.89)	1–12	166(58.5)
	13–60	102(35.9)
	≥ 61	16(5.6)
Current treatment	No active treatment	75(26.4)
	Chemotherapy	190(66.9)
	Radiotherapy	10(3.5)
	Surgery	9(3.2)
Functional status (M = 4.49; SD = 1.9)	≤2 (severely impaired)	70(24.6)
	3–5 (moderately impaired)	55(19.4)
	6 (fully functional)	159(56.0)
Patient's pain rating	≤3 (mild)	13(4.6)
	4–6 (moderate)	63(22.3)
	7–8 (severe)	89(31.2)
	9–10 (very severe)	119(41.9)
Duration of pain (in months) (M = 21.4; SD = 3.8)	1–12	164(57.7)
	13–60	98(34.5)
	≥ 61	22(7.8)
Ranking of the most disturbing symptoms (*multiple response*)	Pain (1st)	210(73.9)
	No appetite/general weakness (2nd)	46(16.2)
	Nausea/inability to move/lack of sleep (3rd)	19(6.7)
	Feeling tired of hospital(4th)	24(8.4)

M mean, *SD* standard deviation

Factors associated with FCG knowledge and self-efficacy for pain management

As shown in Table 5, a high perceived impact of caregiving on physical health ($p = 0.005$), poor self-rated health ($p = 0.003$) and severe ACP's pain ($p = 0.023$) were significantly associated with a low FCGs' knowledge. The SE for pain management was significantly associated with perceived impact of caregiving role on FCGs' physical well-being ($p = 0.019$), weekly hours of caregiving ($p = 0.008$), having a chronic illness ($p = 0.024$) and receiving organisational support ($p = 0.001$). The other factors did not reach significance level.

Predictors of FCGs' knowledge and self-efficacy for pain management

The Hosmer and Lemeshow goodness-of-fit test results, knowledge scores [χ^2 (8, $n = 284$) = 3.262, $p = 0.917$] and self-efficacy scores [χ^2 (7, $n = 284$) = 7.009, $p = 0.428$] showed that the model predicted values were not significantly ($p > 0.05$) different from the observed values. FCGs' self-rated health (OR = 1.746, CI = 1.024–2.978) significantly predicted FCGs' knowledge level. The results in Table 6 show that FCGs with low self-rated health were twice more likely to have low knowledge compared to those with good self-rated health. The perceived impact of caregiving role on

Table 3 Family caregivers' experience with patients' pain

Variable	Response	$N = 284$ Frequency (%)	Mean ± standard deviation
Patient's pain over the past week	≤ 3 (mild)	32(11.3)	7.3 ± 2.6
	4–6 (moderate)	64(22.5)	
	≥ 7 (severe)	188(66.2)	
Patient's pain currently	≤ 3 (mild)	52(18.3)	6.14 ± 2.9
	4–6 (moderate)	93(32.8)	
	≥ 7 (severe)	139(48.9)	
Pain relief currently attained	≤ 3 (great deal)	96(33.8)	4.75 ± 2.8
	4–6 (moderate)	111(39.1)	
	≥ 7 (no or mild)	77(27.1)	
Patient's suffering due to pain	≤ 3 (mild)	15(5.3)	8.51 ± 2.2
	4–6 (moderate)	32(11.3)	
	≥ 7 (great deal)	237(83.5)	
FCG's suffering due to patient's	≤ 3 (mild)	24(8.5)	8.11 ± 2.5
	4–6 (moderate)	35(12.3)	
	≥ 7 (great deal)	225(79.2)	
Ability to control patient's pain	≤ 3 (great deal)	77(27.1)	5.39 ± 2.9
	4–6 (moderate)	111(39.1)	
	≥ 7 (no or little)	96(33.8)	
Expected pain level in future	≤ 3 (mild)	167(58.8)	3.5 ± 3.3
	4–6 (moderate)	61(21.5)	
	≥ 7 (severe)	56(19.7)	
Use of non-drug pain control methods	Yes	98(34.5)	--n/a
	No	186(65.5)	

FCG family caregiver, *M* mean, *SD* standard deviation

physical health (OR = 1.551, CI = 1.074–2.239), caregiving hours per week (OR = 0.519, CI = 0.315–0.845) and receiving organisational support (OR = 0.388, CI = 0.222–0.679) significantly predicated SE. FCGs who perceived high caregiving impact on their physical health were 1.5 times more likely to have low SE compared to those reporting a low impact level. For every 1 point increase in weekly hours of caregiving, the odds of SE increased by 0.52. For every 1 point increase in the receipt of organisational support, the odds of SE decreased by 0.4. The Wald statistic was used to evaluate whether the logistic coefficient (B) for each of the predictors was different from zero. Therefore, FCGs' self-rated health ($p < 0.05$) is a significant predictor of the FCGs' knowledge level for pain management. The Wald statistics also shows that the impact of caregiving on physical well-being ($p < 0.05$), caregiving hours per week ($p < 0.05$) and organisation support ($p < 0.01$) significantly predicted FCGs' SE for pain management.

Discussion

To our knowledge, this is the first study to assess FCGs' knowledge and SE for cancer pain management in sub-Saharan Africa. The findings show that FCGs mostly lacked adequate knowledge about pain management when caring for ACPs (52%), although they were caring for ACPs who mostly had advanced cancer disease and experienced severe pain

Table 4 Family caregivers' knowledge and self-efficacy for pain management in ACPs

Variable	Level	$N = 284$ Frequency (%)	M (SD)	95% CI
Knowledge	FCG with high knowledge	136 (47.9)	41.7(14.05)	40.1–43.4
	FCG with low knowledge	148 (52.1)		
SE	FCG with high self-efficacy	135(47.5)	795.95(301.3)	760.76–831.14
	FCG with low self-efficacy	149(52.5)		

FCG family caregiver, *SE* self-efficacy, *M* mean, *SD* standard deviation

Table 5 Factors associated with FCGs' knowledge and self-efficacy for pain management

Factor	Response	Frequency $n = 284$ F (%)	FCG High knowledge $n = 136$ F (%)	FCG Low knowledge $n = 148$ F (%)	Chi-square p value
Impact on physical health	4–8	126(44.4)	74(58.7)	52(41.3)	$\chi^2 = 10.708$ $p = 0.005^{**}$
	9–13	121(42.6)	48(39.7)	73(60.3)	
	14–18	37(13)	14(37.8)	23(62.2)	
Self-rated health	Good (1–5)	184(64.8)	100(54.3)	84(45.7)	$\chi^2 = 8.740$ $p = 0.003^{**}$
	Poor (≥ 6)	100(35.2)	36(36)	64(64)	
Patient's pain level	≤ Moderate[a]	145(51.1)	79(54.5)	66(45.5)	$\chi^2 = 5.164$ $p = 0.023^{*}$
	≥ Severe[b]	139(48.9)	57(41)	82(59)	
Duration as FCG (months)	≤ 11	135(47.5)	72(53.3)	63(46.7)	$\chi^2 = 5.986$ $p = 0.05^{*}$
	12–24	91(32)	34(37.4)	57(62.6)	
	> 24	58(20.4)	30(51.7)	28(48.3)	
			High SE $N = 149$ F (%)	Low SE $N = 135$ F (%)	
Impact on physical well-being	4–8	126 (44.4)	74(58.7)	52(41.3)	$\chi^2 = 7.945$ $p = 0.019^{*}$
	9–13	121(42.6)	63(52.1)	58(47.9)	
	14–18	37 (13)	12(32.4)	25(67.6)	
Hours of caregiving per week	≤ 120	149(52.5)	67(45)	82(55)	$\chi^2 = 7.067$ $p = 0.008^{**}$
	> 120	135(47.5)	82(60.7)	53(39.3)	
Having a chronic illness	Yes	73(25.7)	30(41.1)	43(58.9)	$\chi^2 = 5.092$ $p = 0.024^{*}$
	No	211(74.3)	119(56.4)	92(43.6)	
Receiving organisational support	Yes	79(27.8)	29(36.7)	50(63.3)	$\chi^2 = 10.894$ $p = 0.001^{**}$
	No	205(72.2)	120(58.5)	85(41.5)	

[a] Pain rating score ≤ 6

[b] Pain score ≥ 7

FCG family caregiver, *SE* self-efficacy

$^{*}p < 0.05$, $^{**}p < 0.01$

levels. This is consistent with other reports on FCGs' knowledge on pain management while at home [32, 33]. The inadequate understanding of the key aspects of pain management may be due to the lack of preparation for the task, lack of access to information and on-going support for pain management [18]. Literature shows that occasionally, FCGs receive brief and disjointed explanations about cancer pain and its management from HCPs or friends, with no support for the evolving concerns and information needs related to the nature of pain, management strategies, management of medication side effects, painful crises and the expected outcomes. The FCGs are left with no option but to use personal experiences, and this may result in lack of confidence, poor decision making, feelings of helplessness and inadequacy when supporting ACPs [16].

Other studies show that the level of FCGs' knowledge is significantly influenced by their understanding of specific aspects of cancer pain and the management process [10].

Table 6 Predictors of family caregivers' knowledge and self-efficacy for pain management ($N = 284$)

	Factor	B	Wald	P value	Exp (B) (OR)	95% CI
Knowledge for cancer pain management	Impact on physical health	0.363	3.536	0.060	1.437	0.985–2.098
	Self-rated health	0.558	4.193	0.041^{*}	1.746	1.024–2.978
	Patient's pain level	0.424	2.902	0.088	1.528	0.938–2.489
	Duration as FCG	0.420	2.909	0.088	1.522	0.939–2.466
FCG self-efficacy	Impact on physical well-being	0.439	5.480	0.019^{*}	1.551	1.074–2.239
	Hours of caregiving per week	− 0.657	0.254	0.010^{*}	0.519	0.315–0.854
	Having a chronic illness	− 0.553	0.293	0.059	0.575	0.324–1.021
	Receiving organisational support	− 0.946	0.285	0.001^{**}	0.388	0.222–0.679

FCG family caregiver, *B* logistic coefficient, *OR* odds ratio

$^{*}p < 0.05$, $*^{*}p < 0.01$

Therefore, there is need for deliberate interventions aimed at improving FCGs' knowledge and SE for pain management [32, 34]. Similar to our study, Lee and colleagues [35] found that FCGs mostly lack understanding of concepts such as dependence and tolerance and hold strong beliefs about the meaning of pain intensity and cancer disease progression. These findings are important because adequate knowledge and skills enhances FCGs' coping with the caregiving role [36] and inadequate knowledge is a barrier to optimal pain control in ACPs. The other exemplar of the negative effects of FCGs' knowledge deficits on ACPs' pain management practices are the findings of a significant correlation between FCGs' hesitancy to use prescribed analgesic while at home and ACP intense pain levels [35].

In this study, FCGs' poor self-rated health predicted low knowledge level. It is logical to conclude that FCGs with low knowledge levels tend to find caregiving for ACP experiencing pain to be very challenging. Earlier studies show that constant frustration among FCGs ultimately impacts their well-being both physically and psychologically [10, 21]. Coping with the care demands of ACPs requires knowledge, positive attitudes, and skills because these are key to actual provision of care [36, 37]. Therefore, improving the FCGs' knowledge for pain management at home may also promote their well-being.

Self-efficacy (SE) is a very crucial construct to the FCGs' appraisal of the caregiving role [36]. Within the caregiving context, FCGs need to positively perceive their ability to competently perform the needed care in order to achieve desired outcomes [38, 39]. In the current study, FCGs reported moderate SE for pain management. This is consistent with other studies [40, 41]. Other reports show that FCGs who perceive high efficacy for pain management tend to report less pain and fatigue, better mood state and physical functioning among their ACPs [31]. On the other hand, a reduction in FCGs' SE is associated with an increament in caregiving strain among unsupported FCGs [42]. Yet, FCGs' attributes tend to progressively decline during cancer disease [43] with SE level at one point predicting future efficacy [44]. This implies that the moderate efficacy level for pain management among FCGs in the current study may reduce, or remain the same in future. Therefore, interventions to augment and sustain efficacious beliefs among FCGs are needed in order to enhance and ensure optimal pain management among ACPs and FCGs' well-being, especially in resource-limited settings where most of the cancer care provided in outpatient settings.

In this study, the perceived high impact of caregiving on FCGs' physical health significantly predicted low SE for pain management. This is in line with Bandura's [38] posting that better physical well-being enhances one's efficacy beliefs. Given the influence of SE on one's ability to initiate and sustain adaptive coping strategies [38], it is possible that low FCGs' perceived SE is associated with inaction to alleviate ACPs' pain leading to suboptimal pain control. Our findings corroborate the evidence that FCGs' SE may boost their well-being and ACPs' pain management [45].

According to Bandura, repeated task performance coupled with performance accomplishment and positive outcome promotes a sense of mastery and enhance SE beliefs [38]. This may explain the predictive relationship observed between hours of caregiving and the FCGs' SE for pain management. The finding is consistent with literature [45]. However, extended hours of caregiving may also be detrimental to physical, mental and social well-being of FCGs [42]. Therefore, interventions to facilitate FCGs' attainment of high SE should not malign FCGs' health outcomes.

Conclusions

The FCGs of ACPs had moderate levels of knowledge and SE for pain management at home. The self-rated health and impact of caregiving on physical health predicted FCGs' knowledge and SE. Interventions to enhance FCGs knowledge and SE need to be well thought about since the receipt of organisational support predicted low SE for pain management in ACPs.

Implications for clinical practice

FCGs are critical to the continuity of pain management and achievement of optimal pain control in ACPs. In Uganda, a resource-limited country, supportive interventions focusing on education and care to enhance FCGs' knowledge, attitudes, self-efficacy and skills for cancer pain management should be deliberately integrated in the cancer care to ensure well-managed cancer pain and well-being of FCGs while at home.

Strength and limitations of the study

The consecutive recruited of participants may limit the generalisability of study findings. However, the sample size was large enough. The reliability and validity of the scales were checked with the Ugandan context. This helped the study to generate findings that could be compared to other parts of the world.

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Availability of data and materials The datasets supporting the conclusions of this article are included within the article.

Authors' contribution IBK wrote the concept of the study. All authors participated in designing the study, data analysis and drafting of the manuscript and approved the final manuscript.

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Compliance with ethical standards

The study was approved by HAU, UCI (REO/AC/02) and the Uganda National Council of Science and Technology (SS4003). The participants provided written informed consent.

Conflict of interests The authors declare that they have no conflict of interest. The authors have full control of the primary data and agree to allow the journal to review the data if requested.

References

1. Palos GR, Mendoza TR, Liao K et al (2011) Caregiver symptom burden: the risk of caring for an underserved patient with advanced cancer. Cancer 117:1070–1079. https://doi.org/10.1002/cncr.25695
2. Stark L, Tofthagen C, Visovsky C, McMillan SC (2012) The symptom experience of patients with cancer. J Hosp Palliat Nurs 14:61–70. https://doi.org/10.1097/NJH.0b013e318236de5c
3. Higginson IJ, Murtagh FE, Osborne TR (2013) Epidemiology of pain in cancer. http://link.springer.com/chapter/10.1007/978-0-85729-230-8_2#page-1. Accessed 16 June 2015
4. McCarthy B (2011) Family members of patients with cancer: what they know, how they know and what they want to know. Eur J Oncol Nurs 15:428–441. https://doi.org/10.1016/j.ejon.2010.10.009
5. den Beuken-van Everdingen MHJ V, De Rijke JM, Kessels AG, Schouten HC, Van Kleef M, Patijn J (2007) Prevalence of pain in patients with cancer: a systematic review of the past 40 years. Ann Oncol 18:1437–1449. https://doi.org/10.1093/annonc/mdm056
6. Namukwaya E, Leng M, Downing J, Katabira E (2011) Cancer pain management in resource –limited settings: a practice review. Pain Res treat. http://www.hindawi.com/journals/prt/2011/393404/abs. Accessed on 4th January 2018, p 1, 6
7. Harding R, Selman L, Agupio G, Dinat N, Downing J, Gwyther L, Mashao T, Mmoledi K, Sebuyira LM, Ikin B, Higginson IJ (2011) The prevalence and burden of symptoms among cancer patients attending palliative care in two African countries. Eur J Cancer 47:51–56. https://doi.org/10.1016/j.ejca.2010.08.003
8. Hökkä M, Kaakinen P, Pölkki T (2014) A systematic review: non-pharmacological interventions in treating pain in patients with advanced cancer. J Adv Nurs 70:1954–1969. https://doi.org/10.1111/jan.12424
9. Hjernstad MH, Haugen DF, Bennett MI, Kaasa S (2012) Pain assessment tools in palliative cancer care. In: Moore RJ (ed) Handbook of pain and palliative care: biobehavioral approaches for the life course. Springer, New York, pp 71–75
10. Kwom JH (2014) Overcoming barriers in cancer pain management. J Clin Oncol 32:1727–1733. https://doi.org/10.1200/JCO.2013.52.4827
11. Merriman A, Harding R (2010) Pain control in the African context: the Ugandan introduction of affordable morphine to relieve suffering at the end of life. Philos Ethics Humanit Med 5:10. https://doi.org/10.1186/1747-5341-5-10
12. Luckett T, Davidson PM, Green A, Boyle F, Stubbs J, Lovell M (2013) Assessment and management of adult cancer pain: a systematic review and synthesis of recent qualitative studies aimed at developing insights for managing barriers and optimizing facilitators within comprehensive framework of patient care. J Pain Symptom Manag 46:229–253. https://doi.org/10.1016/j.jpainsymman.2012.07.021
13. Swarm R, Abernethy AP, Anghelescu DL, Benedetti C, Blinderman CD, Boston B, Cleeland C, Coyle N, Deleon-Casasola OA, Eilers JG, Ferrell B, Janjan NA, Karver SB, Levy MH, Lynch M, Moryl N, Murphy BA, Nesbit SA, Oakes L, Obbens EA, Paice JA, Rabow MW, Syrjala KL, Urba S, Weinstein SM, NCCN Adult Cancer Pain (2010) Adult cancer pain. J Natl Compr Cancer Netw 8:1046–1086. https://doi.org/10.6004/jnccn.2010.0076
14. Gordon DB, Dahl JL, Miaskowski C, McCarberg B, Todd KH, Paice JA, Lipman AG, Bookbinder M, Sanders SH, Turk DC, Carr DB (2005) American pain society recommendations for improving the quality of acute and cancer pain management: American pain society quality of care task force. Arch Intern Med 165:1574–1580. https://doi.org/10.1001/archinte.165.14.1574
15. Muliira JK, Kizza IB, Nakitende G (2013) Roles of family caregivers and perceived burden when caring for hospitalized adult cancer patients: perspective from a low income country. Cancer Nursing. https://doi.org/10.1097/NCC.0000000000000591
16. Kelley M, Demiris G, Nguyen H, Oliver DP, Wittenberg-Lyles E (2013) Informal hospice caregiver pain management concerns: a qualitative study. Palliat Med 27:673–683. https://doi.org/10.1177/0269216313483660
17. Mehta A, Cohen SR, Carnevale FA, Ezer H, Ducharme F (2010) Family caregivers of palliative cancer patients at home: the puzzle of pain management. J Palliat Care 26:184–193
18. Meeker MA, Finnell D, Othman AK (2011) Family caregivers and cancer pain management: a review. J Fam Nurs 17:29–60. https://doi.org/10.1177/1074840710396091
19. Given BA, Given CW, Sherwood P (2012) The challenge of quality cancer care for family caregivers. Semin Oncol Nurs 28:205–212. https://doi.org/10.1016/j.soncn.2012.09.002
20. Oliver DP, Demiris G, Wittenberg-Lyles E, Porock D, Collier J, Arthur A (2010) Caregiver participation in hospice interdisciplinary team meetings via videophone technology: a pilot study for pain management. Am J Hosp Palliat Med 27:465–473. https://doi.org/10.1177/1049909110362402
21. Robinson CA, Pesut B, Bottorff JL (2012) Supporting rural family palliative caregivers. J Fam Nurs 18:467–490. https://doi.org/10.1177/1074840712462065
22. Okuku F, Omoding A, Walusansa V, Origa M, Mutungi G, Orem J (2013) Infection- related cancers in sub-Saharan Africa: a paradigm for cancer prevention and control. Oncology 84(2):75–80
23. Hospice Africa Uganda (2013) Annual report. https://www.hospice_africa_uganda_annual_report_2013.pdf. Accessed on 25th Dec 2014
24. Ferrell B, Rhinner M, Rivera LM (1993) Development and evaluation of the family pain questionnaire. J Psychosoc Oncol 10:21–35. https://doi.org/10.1300/J077V10N04_02
25. Anderson KO, Dowds BN, Pelletz RE, Edwards WT, Peeters-Asdourian C (1995) Development and initial validation of a scale to measure self-efficacy beliefs in patients with chronic pain. Pain 63:77–83. https://doi.org/10.1016/0304-3959(95)00021-J
26. Given CW, Given B, Stommel M, Collins C, King S, Franklin S (1992) The caregiver reaction assessment (CRA) for caregivers to persons with chronic physical and mental impairments. Res Nurs Health 15:271–283. https://doi.org/10.1002/nur.4770150406
27. Katz S, Downs TD, Cash HR, Grotz RC (1970) Progress with development of the index of ADL. Gerontologist 10:20–30. https://doi.org/10.1093/geront/10.1_Part_1.20
28. Waltz FC, Strickland OL, Lenz RE (2010) Measurement in nursing and Health Research, 4th edn. Springer, New York

29. Ferrell BR, Grant M, Borneman T, Juarez G, Veer AT (1999) Family caregiving in cancer pain management. J Palliat Med 2: 185–195. https://doi.org/10.1089/jpm.1999.2.185
30. Campbell LC, Keefe FJ, McKee DC et al (2004) Prostate cancer in African Americans: relationship of patient and partner self-efficacy to quality of life. J Pain Symptom Manag 28:433–444. https://doi.org/10.1016/j.jpainsymman.2004.02.020
31. Porter LS, Keefe FJ, Garst J, McBride CM, Baucom D (2008) Self-efficacy for managing pain, symptoms, and function in patients with lung cancer and their informal caregivers: associations with symptoms and distress. Pain 137:306 – 315. https://doi.org/10.1016/j.pain.2007.09.010
32. Nijboer C, Triemstra M, Tempelaar R, Sanderman R, van den Bos GAM (1999) Measuring both negative and positive reactions to giving care to patients: psychometric qualities of the caregiver reaction assessment. Soc Sci Med 48:1259–1269. https://doi.org/10.1016/S0277-9536(98)00426-2
33. Valeberg BT, Kolstad E, Smastuen MC, Miaskowski C, Rustoen T (2013) The PRO-SELF pain control program improves family caregivers' knowledge of cancer pain management. Cancer Nurs 36: 429–435. https://doi.org/10.1097/NCC.0b013e3182747bcf
34. Chi NC, Demiris G (2017) Family caregivers' pain management in end-of-life care: systematic review. Am J Hosp Palliat Med 34:470–485. https://doi.org/10.1177/1049909116637359
35. Lee BO, Lui Y, Wang YH et al (2015) Mediating effect of family caregivers' hesitancy to use analgesics on homecare cancer patients' analgesic adherence. J Pain Symptom Manag 50:814–821. https://doi.org/10.1016/j.jpainsymman.2015.06.014
36. Fletcher BS, Miaskowski C, Given B, Schumacher K (2012) The cancer family caregiving experience: an updated and expanded conceptual model. Eur J Oncol Nurs 16:387–398. https://doi.org/10.1016/j.ejon.2011.09.001
37. Methta A, Chan LS, Cohen SR (2014) Flying blind: sources of distress for family caregivers of palliative cancer patients managing pain at home. J Psychosoc Oncol 32:94–111. https://doi.org/10.1080/07347332.2013.856057
38. Bandura A (1998) Health promotion from the perspective of social cognitive theory. Psychol Health 13:623–649. https://doi.org/10.1080/08870449808407422
39. Steffen AM, McKibbin C, Zeiss AM, Gallagher- Thompson D, Bandura A (2002) The revised scale for caregiving self-efficacy reliability and validity studies. J Gerontol B Psychol Sci Soc Sci 57:P74–P86. https://doi.org/10.1093/geronb/57.1.P74
40. Hendrix CC, Landerman R, Abernethy AP (2013) Effects of an individualised caregiver training intervention on self-efficacy of cancer caregivers, West J Nurs Res. 35:590–610. https://doi.org/10.1177/0193945911420742
41. Hendrix CC, Bailey DE Jr, Steinhauser KE et al (2016) Effects of enhanced caregiver training program on cancer caregiver's self-efficacy, preparedness, and psychological well-being. Support Care Cancer 24:327–336. https://doi.org/10.1007/s00520-015-2797-3
42. Wadhwa D, Burman D, Swami N, Rodin G, Lo C, Zimmermann C (2013) Quality of life and mental health in caregivers of outpatients with advanced cancer. Psychooncology 22:403–410. https://doi.org/10.1002/pon.2104
43. Keefe FJ, Ahles TA, Sutton L et al (2005) Partner guided cancer pain management at the end-of-life: a preliminary study. J Pain Symptom Manage 29:263–273. https://doi.org/10.1016/j.jpainsymman.2004.06.014
44. Kershaw T, Ellis KR, Yoon H, Schafenacker A, Katapodi M, Northouse L (2015) The interdependence of advanced cancer patients' and their family caregivers' mental health, physical health, and self-efficacy over time. Ann Behav Med 49:901–911. https://doi.org/10.1007/s12160-015-9743-y
45. Deshields TL, Rihanek A, Potter P, Zhang Q, Kuhrik M, Kuhrik N, O'Neill JA (2012) Psychosocial aspects of caregiving: perceptions of cancer patients and family caregivers. Support Care Cancer 20: 349–356. https://doi.org/10.1007/s00520-011-1092-1