



# The Influence of a Home-Based Education Intervention on Family Caregivers' Knowledge and Self-Efficacy for Cancer Pain Management in Adult Patients Within a Resource-Limited Setting

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## Abstract

Cancer-related pain is prevalent and has debilitating effects on patients and their family. The effects of cancer pain can be curtailed if the family members caring for the patient receive essential support to enhance their capabilities for cancer pain management. Little has been done to study the available support to family caregivers (FCGs) towards pain management in adult cancer patients (ACPs) living in resource-limited countries where the burden of cancer is on the rise. This study evaluated the influence of an education intervention delivered in the home setting on FCGs' knowledge and self-efficacy (SE) for pain management in ACPs. One-group pre-/post-test design was used in a sample of 54 FCGs who had been caring for ACPs suffering from pain for at least 1 month. Data were collected using the Family Pain Questionnaire and Caregiver Pain Management SE Scale. The FCGs' mean knowledge score post-intervention ( $26.69 \pm 10$ ) was higher than the baseline ( $45 \pm 12.9$ ), and the difference was statistically significant ( $t = 10.382$ ,  $p = 0.000$ ,  $CI = 17.12-25.43$ ). Additionally, the FCGs' mean SE score post-intervention ( $1003.30 \pm 191$ ) was higher than the baseline ( $648.3 \pm 273.4$ ), and the difference was statistically significant ( $t = -8.52$ ,  $p = 0.000$ ,  $CI = -438.6-271.4$ ). The home-based education intervention significantly and positively influenced the FCGs' knowledge and SE for pain management while at home. Cancer pain management educational interventions delivered at home should be considered as one of the strategies for enhancing cancer care in resource limited settings.

**Keywords** Pain management · Cancer pain · Home care · Education · Family caregiver · Peer support

## Introduction

Cancer is a complex chronic disease associated with debilitating effects on the lives of over 32.6 million people worldwide [1]. A significant part of the effects of cancer arise from the associated physical, social, and psychological symptom burden that may include breathing difficulties, sleeping difficulties, worry, fatigue, medication side effects, and pain [2]. Of all the above components of the symptom burden, pain is

highly prevalent and afflicts all patients regardless of the cancer stage or type with severest effects among patients with advanced cancer disease [3, 4]. The overall prevalence of cancer-related pain stands at 45.6%, but this rate increases during active anti-cancer treatment (59%) and among those with advanced disease stage (73.9%) [3]. The problem of cancer pain also affects cancer survivors with 33% of them reporting intense pain up to 5 years post-treatment [5].

In resource-limited settings, the high prevalence of moderate to severe pain (30 to 70%) among adult cancer patients (ACPs) [6] is attributed to the limited access to essential analgesics and late cancer diagnosis [7, 8]. In Uganda (a resource-limited country located in sub-Saharan Africa), ACPs are reported to experience an average of 18 symptoms within a cluster of physical and psychological symptoms, and for the large majority (87%) pain is the most severe symptom despite efforts to promote increased availability and access to oral morphine [6–8]. The unrelieved pain is not only associated with poor quality of life in ACPs but also negatively impacts the well-being of the patients' family members. Literature shows that the family members (family caregivers) caring

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for ACPs suffering from pain report more complaints of sadness, depressive symptoms, anxiety, fear, fatigue, loss of appetite, and sleep disturbance compared to family caregivers (FCGs) of ACPs without pain [9, 10]. These experiences lead ACPs and their FCGs to fear pain and highly rank the need for its control as a major priority [11].

In an effort to ensure effective cancer pain management, the National Comprehensive Cancer Network (NCCN) and American Pain Society set specific guidelines and recommendations to emphasize a holistic, comprehensive, multidisciplinary, and multilevel approach to cancer pain management [12, 13]. Similarly, the biopsychosocial model recognizes the multi-dimensional nature of cancer pain, and focuses on the somatic, psychological, and social aspects of the affected patient during pain management. This implies that the use of pharmacological and non-pharmacological methods for cancer pain management, an interdisciplinary team, ensuring patient and FCG involvement, and social support are key attributes to quality cancer pain management [12]. If embraced well, the above guidelines and recommendations foster a family-centered approach that ensures shared decision making, active involvement and consideration of ACP preferences and values in a collaborative manner, thereby promoting optimal pain control, coping, and well-being of the ACPs and their FCGs [12, 13]. If these key standards are operationalized, it is projected that 80 to 90% of ACPs can achieve adequate pain relief [3]. However, until today, only slight improvements in cancer pain management have been realized and a large proportion of ACPs (43%) continue to suffer from inadequately managed pain [3].

In view of the social context of cancer pain, it is important to emphasize the role of the FCGs in achieving quality pain management for ACPs. The FCGs play key roles while the ACPs are at home, and these may include assessing the ACP's level of pain, administering the prescribed analgesics, managing associated symptoms and medication side effects, applying non-pharmacological methods, monitoring ACP's response to instituted interventions, providing emotional comfort and support to the ACP, and reporting to the health care providers (HCPs) about the progression of the ACPs' pain experience and effectiveness of the interventions [14]. In a setting of limited health care human resources, cancer care services, and other facilities, the FCGs serve a critical role in ensuring the continuity of care related to cancer and pain management because many ACPs depend on their FCGs for basic care, support, and comfort while at home and during hospitalization.

The performance of caregiver roles and tasks related to the control of ACPs' pain while at home has been shown to precipitate emotional distress, and this is seen in FCGs' feelings of frustration, uselessness, helplessness, worry, anxiety, anger, and chronic sorrow, especially when the ACP experiences pain, which is perceived to be uncontrollable [4]. Indeed, FCGs cite pain management as one of the most challenging

caregiving tasks because many times they assume the caregiver role abruptly, and without any formal support or assistance from HCPs [15]. The challenges arise mostly because of the FCG's deficits in knowledge, skills, and experience related to pain management, and low perceived self-efficacy (SE) for related decision making [11].

Given the pivotal role of FCGs in cancer pain management, it is evident that they need to be supported and empowered if they are to effectively contribute to the process of achieving optimal pain control for ACPs [16]. The development of pain educational interventions for patients and their families is a strongly recommended strategy to minimize the barriers to adequate cancer pain management while at home [17]. Similarly, systematic reviews of interventional studies among FCGs show that education and skill training interventions lead to benefits such as positive appraisal of the caregiving experience, improved knowledge and SE, positive coping, and psychological well-being [18]. Until today, there is no study which has explored implementation of an educational intervention for FCGs of ACPs experiencing pain in resource-limited settings of sub-Saharan Africa. The purpose of this study was to evaluate the influence of a FCG education intervention for home management of cancer pain on their knowledge and SE for cancer pain management in ACPs.

## Methods

### Design and Setting

A single group pre/post-test design was used to implement a FCG education intervention (from April 2016 to October 2016) within the homes shared by the ACPs and their FCGs. Data were collected at baseline (time 1) and at the end of the 3-month follow-up period (time 2). The study participants were living with in the catchment area of Hospice Africa Uganda (HAU) and Uganda Cancer Institute (UCI). Uganda has one of the highest cancer morbidity (200,000 cases per year) and mortality (46,970 deaths per year) [19] and the majority of the ACPs (80%) present with late stage disease due to lack of awareness, cost of care, and inaccessible cancer care services [20]. The UCI is the main governmental provider of cancer care services (research, screening, diagnosis, and treatment) and registers 4000 new cases every year, which is 4% of all new cases in the country. The cancer care at UCI is largely inaccessible due to constant shortage of medications, diagnostic facilities, and oncology specialists. For instance, Uganda has a need of 5800 palliative care specialists and has only one poorly maintained external beam radiotherapy machine located at Mulago National Referral Hospital (MNRH) complex to which UCI is affiliated [19, 20]. The Palliative Care Association of Uganda (PCAU) and HAU are the main non-governmental providers of palliative care services, with the

later serving as the center of excellence since its inception in 1993. The HAU supports the operation of a palliative care unit which was established in 2008 by MNRH and Makerere University, prepares and distributes oral morphine in collaboration with Joint Medical stores. The PCUA and HAU, in collaboration with the Uganda Ministry of Health, integrated palliative care into the national health system and educational curricula, developed clinical guidelines, expanded mandated prescribers of opioids to include trained nurses and clinical officers, and supported registration of oral morphine as an essential drug by the Uganda National Drug Authority [6, 7]. The successes such as the inclusion of community providers (family and volunteers) in palliative care planning and implementation, and research in palliative care have been registered with increased cancer patients' access to oral morphine and home-based palliative care services [19–21]. The development of the national framework for palliative care services, supporting of FCGs through provision of information, education and supervision by nurses, use of community volunteer teams, training of palliative care specialists, increasing access to analgesics, and designing safe storage facilities for opioids are some of the recognized strategies to strengthen the current palliative service delivery in Uganda [19–21]. However, the strategies require more evidence through research to guide decision making.

## Ethics

Ethical review and approval was received from the research and ethics committees of HAU, UCI (UCI REO/AC/02), and the Uganda National Council of Science and Technological (UNCST SS4003). All the participants received clear explanation of the study purpose, extent of participation, and the nature of the intervention before providing written informed consent.

## Study Participants

The sample was comprised of 54 FCGs of ACPs who were clients of HAU and UCI. The FCGs were included in the study if aged 18 years and above, caring for an ACP (aged at least 18 years) who had pain for at least 1 month and with a confirmed cancer diagnosis, shared household with the ACP, had taken care of the ACP for at least 1 month and expected continuation of the caregiving role for at least 4 months, and able to speak grade four English or Luganda (the commonly spoken languages). The FCGs were excluded if their ACPs were referred from another country, they were hired individuals, and reported history of cancer and/or a mental disorder.

## Intervention

The FCG education intervention was composed of two components guided by a study protocol. The first component that

included two interactive one-on-one training sessions (each lasting 45 to 60 min) was conducted by a single palliative care nurse (during two home visits) using content compiled in a study booklet. The content on characteristics and sources of cancer pain and management principles was covered during the first training session while the second session focused on details of cancer pain assessment and management, and concepts such as addiction, tolerance, drug abuse, and dependence, “around-the-clock” and “as-needed” treatment. For example, the nurse instructed the FCG on how to use the scales (numerical, FACES, and verbal descriptor) to assess pain and the non-pharmacological management techniques, with the FCGs' most preferred method discussed and demonstrated in detail. The nurse also demonstrated documentation of findings in the pain diary (part of the study booklet) upon assessing the ACP's pain with an appropriate pain scale. Deliberately, time for FCGs to ask questions, seek clarification, and to address misconceptions was provided. The FCGs received supportive feedback upon return demonstrations. The FCGs were encouraged to refer to the provided study booklet during patient care and use it to record pain management information including time and date of ACPs' pain episode, pain score before and after intervening, the non-pharmacological method used, medication given if any, and any other associated problems. The FCGs were encouraged to continue supporting the ACPs to take medications as prescribed and to contact the study nurse anytime through a provided telephone contact for any clarifications.

The second component of the intervention that included three follow-up support home visits was conducted by a single peer support volunteer (PSV) who lived in close proximity to a particular FCG. Each FCG was visited once every 4 weeks for a period of 12 weeks. The PSVs were former FCGs of ACPs who were trained through interactive lectures, role plays, and return demonstration on how to use the study booklet during two 6-h sessions. The PSVs, using step-by-step approach as guided by the study algorithm, held simple focused discussions on the current ACPs' condition and pain status, and checked on the FCGs' progress with the caregiving role and pain management. During the first 30 min of each visit, the PSVs guided the FCGs to reflect on what they knew and had been doing over the past 4 weeks, and encouraged FCGs to identify areas of improvement and aspects in which they needed more support. The PSVs provided positive encouragement on aspects where FCGs did well to help them appreciate their successes in ACP's pain management. In the last 30 min, the PSVs emphasized the approaches and principles taught during the one-on-one education sessions in an interactive manner using the study booklet. The PSVs also conducted return demonstrations as needed by the FCGs and encouraged them to continue using the study booklet. For any information needs that were away from the focus of the intervention, the FCGs were referred to the nurses at HAU and UCI to receive

the standard care. The PSVs summarized the key points, questions, and concerns raised by the FCGs in a logbook and these were reviewed by the study team after every visit to ensure adherence to the study protocol, and feedback was provided to the PSVs during the debriefing meetings. The study materials were validated by three experts in cancer and pain management and piloted tested on three FCGs. All the visits were scheduled on a day and time agreed upon with the FCG.

## Measures

Data were collected using an interviewer-administered questionnaire that comprised of four sections of FCG's and ACP's demographic characteristics (20 items), the Katz Index of independence in activities of daily living (6 items), Family Pain Questionnaire (16 items) [22], and the modified version of the Cancer Caregiver Self-Efficacy scale (16 items) [23]. The Katz Index of Independence in the activities of daily living [24] was used to assess the ACPs' functional status. Each activity of daily living was rated as either performed independently (= 1) or performed with supervision or assistance (= 0). The total scores on the Katz Index were categorized as full function (= 6), moderate functional impairment (= 4), and severe functional impairment ( $\leq 2$ ). In the current study, the Katz Index had Cronbach's alpha of 0.86.

The Family Pain Questionnaire (FPQ) [22] was used to measure FCGs' knowledge and experience with ACPs' pain management. Item ratings range from "0" (the most positive outcome) to "10" (the most negative outcome), and the selected value shows how best the FCG agrees or disagrees with the statement. Upon tool validation, the revised knowledge subscale had 10 items with possible total scores ranging from 0 to 100. The knowledge level was determined by computing the mean of the 10 items, with lower scores indicating higher knowledge level. In the current study, the Cronbach's alpha for the knowledge and experience subscales of the FPQ were 0.52 and 0.72, respectively. The modified version of the Cancer Caregiver self-efficacy scale [23] was used to assess the FCGs' beliefs about their ability to support the cancer pain management. FCGs responded to each item using a 10-point Likert scale (10 = "very uncertain" to 100 = "very certain"). The mean score of the 16 items was computed to determine the level of self-efficacy (SE), with higher scores indicating high SE. The Cronbach's alpha of the SE scale in the current study was 0.94.

## Data Collection Procedures

During the baseline phase, the eligible participants were identified through the out-patient and home-based services at UCI and HAU. The ACPs with multiple FCGs were asked to identify one person who had the main responsibility for their care. Before the baseline survey, the FCGs were informed about

both the baseline and potential opportunity to participate in the intervention. Eligible FCGs provided informed consent prior to completion of the baseline interviewer-administered questionnaire. The FCGs' contact information was recorded on a separate sheet of paper under a code assigned to the filled questionnaire. The FCGs were informed about further communication if the findings of the baseline survey qualified them for the intervention phase. With the help of a list of the codes, the qualified FCGs were reminded about the details of the intervention and requested to re-affirm their willingness to continue with the intervention phase of the study. Scheduling of the first one-on-one session with the study nurse was done via telephone call. Each participant received two one-on-one home-based teaching sessions and three follow-up visits every 4 weeks for 12 weeks from a study nurse and a trained PSV, respectively. The post-intervention data were collected within 3 days after the completion of the three follow-up support home visits.

## Data Analysis

The SPSS version 23 (SPSS Inc., Chicago, IL) was used to perform the data analysis. Baseline characteristics were summarized using descriptive statistics. The Pearson's skewness coefficient and Fisher's measures of skewness and kurtosis were used to evaluate the normality of distribution of the knowledge and SE scores of baseline data, and means were used as cutoff points upon confirming conformity. The paired *t* test analysis (dependent group *t* test) was performed to determine the influence of the intervention on FCG's level of knowledge and SE for cancer pain management at home for ACPs. The significance level was set at less than 0.05 (two-tailed).

## Results

### Characteristics of the Family Caregivers

According to the records available at UCI and HAU, a total of 399 FCGs were eligible for the study, but 283 (70.9%) consented and participated in the study. Of the 283 FCGs, 148 (52.1%) had low knowledge (score > 41.7) and 149 (47.5%) had low SE (score < 79.95). A total of 60 FCGs had both low levels of knowledge and SE, and these were included in the intervention phase of the study. Of the 60 FCGs, 54 (90%) were able to participate and complete the entire intervention (two FCGs withdrew from study due to death of the ACPs, another two shifted from the known residence, and two FCGs exchanged roles with another family member). Therefore, the post-intervention data were collected from 54 FCGs. The characteristics of the 54 FCGs are presented in Table 1 and show a mean age of  $37.6 \pm 14.7$  years.

**Table 1** Demographic characteristics of the family caregivers ( $N = 54$ )

Characteristic of the caregiver	Response	Frequency	%
Age in years (mean = 37.6, SD = 14.7)	18–30	23	42.6
	31–50	20	37.0
	≥ 51	11	20.4
Gender	Male	19	35.2
	Female	35	64.8
Marital status	Single/widow/separated	23	42.6
	Married or living with partner	31	57.4
Relationship with patient	Spouse	11	20.1
	Child	22	38.7
	Other <sup>a</sup>	21	41.2
Employment status	Not employed	25	46.3
	Self-employed	21	38.9
	Company employee	8	14.8
Level of education	≤ Primary school	16	29.7
	Secondary school	24	44.4
	Post-secondary	14	25.9
Length of time as caregiver (in months) (mean = 24.4, SD = 2.79)	1–11	20	37.0
	12–24	21	38.9
	≥ 25	13	24.1
Caregiving hours per week (mean = 113, SD = 55.7)	≤ 40	4	7.4
	41–120	22	40.7
	≥ 121	28	51.9
Number of adults under caregiver's responsibility at home (mean = 1.52, SD = 1.29)	≤ 2	44	81.5
	3–5	10	18.5
Number of children under caregiver's responsibility at home (mean = 2.76, SD = 3.1)	≤ 2	29	53.7
	3–5	19	35.2
	≥ 6	6	11.1
Receives help with the caregiving role	Yes	42	77.8
	No	12	22.2
Receives support from an organization	Yes	28	57.9
	No	26	48.1

SD standard deviation

<sup>a</sup> Other includes sibling, mother, in-law, grandchild, niece, and friend

The majority of FCGs were female (64.8%), unemployed (46.3%), and had attained secondary level education (44.4%). The FCGs had performed the role of caregiver for an average of  $24.4 \pm 2.79$  months and were providing care for an average of  $113 \pm 55.7$  h in a week. A large number of FCGs reported receiving help with the caregiving role (77.8%) and some kind of support from a community organization (57.9%).

### Characteristics of the Adult Cancer Patients

The characteristics of the ACPs are summarized in Table 2. The majority of the ACPs were female (70.4%) with a mean age of  $58.2 \pm 16.1$  years and had been diagnosed with stage 3 or stage 4 cancer (53.7%). On average, the duration since

cancer diagnosis and suffering due to pain was  $27.7 \pm 3.81$  and  $33.7 \pm 6.04$  months, respectively. The commonest type of cancer among the ACPs were cervical (16.7%) and breast (16.7%) cancers..

### Functional Status and Symptom Burden of the Adult Cancer Patients

Table 3 shows the functional status and the symptom burden reported among the ACPs. The ACPs' functional status was moderately impaired (mean =  $4.49 \pm 2$ ) and the majority (53.7%) reported full functional status. On average, each ACP had discomfort from  $4.31 \pm 1.95$  symptoms. All ACPs had pain and the majority reported pain as the most disturbing symptom (72.2%), at severe or very severe (72.2%) level, and

**Table 2** Characteristics of the adult cancer patients (*N* = 54)

Characteristic	Response	Frequency	%
Age in years (mean = 58.2, SD = 16.1)	18–30	3	5.6
	31–50	18	33.3
	≥ 51	33	61.1
Gender	Male	16	29.6
	Female	38	70.4
Marital status	Single/widow/ widower/separated	32	47.9
	Married/having partner	22	52.1
Level of education	≤ Primary school	24	44.4
	Secondary school	8	14.9
	Post-secondary	22	40.7
Cancer diagnosis	Breast cancer	9	16.7
	Cervical cancer	9	16.7
	Colorectal cancer	4	7.4
	Esophageal	5	9.2
	Prostate	3	5.5
	Kaposi's sarcoma	3	5.5
	Leukemia	4	7.4
Others <sup>a</sup>	17	31.6	
Cancer stage	Stage 1	3	5.6
	Stage 2	9	16.7
	Stage 3	18	33.3
	Stage 4	11	20.4
	Cannot be staged	13	24.1
Duration since cancer diagnosis (in months) (mean = 27.7, SD = 3.81)	1–12	28	51.9
	13–60	18	33.3
	≥ 61	8	14.8
Current treatment	No active treatment	20	37.0
	Chemotherapy	32	59.3
	Surgery	2	3.7
Duration of pain (in months) (mean = 33.7, SD = 6.04)	1–12	28	51.9
	13–60	17	31.4
	≥ 61	9	16.7

<sup>a</sup> Others include lymphomas, multiple myeloma, ovarian, uterine, upper GIT, and endocrine cancers

were on pain medications (83.3%). The other common discomforting symptoms were lack of appetite (51.9%) and general weakness (57.4%).

**Influence of the Intervention on FCGs' Knowledge and Self-Efficacy**

The FCGs' mean baseline scores on the knowledge and SE scales were 45.0 ± 12.9 and 648.3 ± 273.4, respectively (Table 4), indicating low knowledge and SE, respectively. The post-intervention mean knowledge and SE scores were 23.69 ± 10.03 and 1003.3 ± 273.4, respectively. A statistically significant decrease ( $t = 10.382, p < 0.001$ ) in the mean knowledge scores after the intervention implies that FCGs were more knowledgeable about cancer pain management after the intervention. The observed increase in the SE mean score after the intervention was also statistically significant ( $t = -8.52, p < 0.001$ ).

**Table 3** Functional status and symptom burden among adult cancer patients (*N* = 54)

Variable	Response	Frequency	%
Functional status (mean = 4.49, SD = 2)	≤ 2 (severely impaired)	14	25.9
	3–5 (moderately impaired)	11	20.4
	6 (fully functional)	29	53.7
Number of symptoms (mean = 4.31, SD = 1.95)	≤ 4	33	61.1
	≥ 5	21	38.9
Timing of pain	Present all the time	22	40.7
	On and off	32	59.3
Patient's pain rating	≤ 3 (mild)	3	5.6
	4–6 (moderate)	12	22.2
	7–8 (severe)	20	37
	9–10 (very severe)	19	35.2
Taking pain medication	Yes	45	83.3
	No	9	16.7
Common symptoms (multiple response)	Pain	54	100
	Lack of appetite	28	51.9
	Lack of sleep	12	22.2
	Inability to move	18	33.3
	General weakness	31	57.4
Ranking of the most disturbing symptoms (multiple response)	Pain (first)	39	72.2
	General weakness (second)	23	42.6
	Lack of appetite/inability to move (third)	18	33.3
	Lack of sleep (fourth)	12	22.2

SD standard deviation

The FCGs' average item scores on the knowledge subscale of FPQ showed significant changes (on 9 out of 10 items) in the understanding of key concepts about cancer pain management with highly significant ( $p = 0.000$ ) differences between baseline and post-intervention scores on the following five items; cancer pain can be effectively managed ( $5.11 \pm 3.45$  vs  $2.49 \pm 3.04, t = 4.196$ ); patient will become dependent on pain medicines overtime ( $5.37 \pm 4.07$  vs  $2.94 \pm 3.37, t = 3.57$ ); important to save the larger doses of analgesics for severe pain levels ( $5.04 \pm 4.09$  vs  $2.06 \pm 3.24, t = 5.82$ ); non-drug methods are effective in relieving pain ( $4.43 \pm 3.39$  vs  $1.89 \pm 2.26, t = 4.55$ ); and if pain is worse, the cancer must be getting worse ( $8.33 \pm 2.67$  vs  $4.67 \pm 3.59, t = 6.776$ ), indicating increased knowledge on the concepts.

The FCGs' average item scores on the FPQ's experience subscale showed significant changes on all items with high statistically significant ( $p = 0.000$ ) differences between baseline and post-education scores on, the extent to which the FCGs felt able to control the ACPs' pain ( $5.78 \pm 2.88$  vs  $3.96 \pm 2.24, t = 3.81$ ) and the expected level of patient's pain in the future ( $4.63 \pm 3.68$  vs  $2.20 \pm 2.89, t = 4.91$ ). The significant differences indicate that FCGs felt more certain about their ability to control ACPs' pain and expected the ACPs' pain to be mild in the future after the intervention. The FCGs significantly ( $t = 3.6, p = 0.001$ ) perceived moderate ACPs' pain level ( $5.89 \pm 2.38$ ) post-intervention as compared to severe

**Table 4** Knowledge and self-efficacy level at baseline and after the education intervention

Paired samples statistics ( <i>N</i> = 54)								
Factor		Mean	SD	SE	Mean difference	<i>t</i> value	<i>p</i> value	95% CI
Family caregivers' knowledge	Baseline	45	12.90	1.76	21.32	10.38	.00-0*	17.12–25.43
	Post-test	23.69	10.03	1.40				
Family caregivers' self-efficacy	Baseline	648.30	273.40	37.20	– 355	– 8.52	.00-0*	– 438.6– – 271.4
	Post-test	1003.30	191	25.90				

SD standard deviation, CI confidence interval, SE standard error

\**p* < 0.05

(7.48 ± 2.63) pain level at baseline. The FCGs expressed moderate pain-related suffering to the ACP (8.30 ± 2.23 vs 6.89 ± 2.93, *t* = 3.34, *p* = 0.002) and to themselves (7.63 ± 2.84 vs 5.91 ± 3.36, *t* = 3.35, *p* = 0.002) after education when compared with the perceived great deal of suffering at baseline.

## Discussion

To our knowledge, this is the first study in Uganda to implement and evaluate a FCGs' education intervention for cancer pain management at home. The FCGs' knowledge and SE for pain management increased significantly after the intervention. As a result of the intervention, the FCGs became more knowledgeable about the concepts related to cancer pain and its management such as addiction and tolerance. The study findings are consistent with those of other studies that focused on FCGs' interventions for cancer pain management [15, 25, 26]. A study examining the effect of a brochure-based education intervention delivered over a period of 3 months found that the intervention led to better understanding of addiction, overdose, and the principles of cancer-related pain management by FCGs of ACPs under palliative care [25]. Similar to the current study, the intervention of training FCGs using a booklet and a telephone-based follow-up led to better FPQ item and total scale scores among FCGs at the end of the training [26]. Other studies have also reported significant increases in the FCGs perceived ability to help ACPs with pain management after the education intervention [27, 28].

The current study delivered the education intervention in the home setting, hence saved the FCGs travel time, cost of transportation, and other difficulties faced by many when trying to access health facilities in Uganda, a country with limited resources and overstretched cancer care services. Additionally, the health care facilities in resource-limited settings many times do not have adequate infrastructure and space to conduct education interventions. Therefore, conducting the education intervention in the FCGs and ACPs' home setting was a safe, affordable, and an effective approach to supporting and

empowering the FCGs, and enhancing access to quality cancer pain management by the ACPs. Other studies that have used a similar approach have also found it to be very beneficial. For instance, after providing information on cancer pain management and facilitating its application within a home setting, Vallerand and colleagues [28] reported improvement in FCGs perceived ability to control ACP's pain. Therefore, intergrating cancer pain management education in home care programs for ACPs should be considered as one of the key strategies needed to enhance access to quality cancer pain management and cancer care in resource-limited settings.

Given the available evidence about unmet needs of information, emotional support, and support for pain management among FCGs of ACPs [29], the results showing improvement in FCG's knowledge and SE for pain management also illuminate the relevance of FCG-focused supportive interventions for cancer pain management as a way of enhancing family involvement and sense of control [30, 31]. The current study allowed FCGs to access the desired information about pain management and to immediately apply it during ACP care within a home caregiving context. The benefit of learning new knowledge and skills that is relevant to the caregiving demands of the FCG could have fostered positive effects such as a change in attitude and retention of acquired knowledge until the end of the 12-week follow-up, with a resultant increase in knowledge and SE [32]. In addition, the study team observed the recommended [32] features of an effective education intervention such as providing simple repeated physical communication using pre-structured written materials that are based on local and international guidelines, and ensured ongoing individualized face-to-face coaching sessions for more than a month at the family's home through PSV. These characteristics have been shown to promote personalized attention to the dyad's needs, allow adequate interaction with consideration to the unique prevailing circumstances, reinforce acquired knowledge and skills, and promote coping among FCGs of ACPs [33, 34].

The observed improvement in the FCGs' knowledge and SE for cancer pain management may also be attributed to the

intensity of the education intervention in the study. The inconsistent report of no significant difference in FCGs' knowledge for pain management after a 4-week home-based education intervention [28] highlights the effects of the limited duration of the intervention and large attrition of participants secondary to death of patients as compared to our study. In our study, the average ACPs' moderate functional impairment limited the attrition rate.

Although our study shares some features with earlier studies reporting similar findings [27, 28], the use of PSVs not only highlights a unique utilization of the informal support network but also represents a re-thinking of resources available in resource-limited settings to enhance cancer care. Literature shows that peer support enhances emotional support, normalizes the caregiving role and coping, with ultimate reduction in the perceived burden and improved quality of life among FCGs of ACPs [35]. It is therefore not surprising that the FCGs perceived lower ACPs' pain levels and less pain-related suffering to the patient and themselves after the intervention.

We recommend further studies of the effectiveness of trained peer support volunteers in regard to enhancing the FCGs' knowledge and SE for cancer pain management at home. If PSVs are found to be effective, this could be one of the needed responses to the persistent suboptimal cancer pain control in resource-limited settings. It is also possible that when FCGs perceived better ability to control the ACPs' pain upon receipt of information and constructive feedback during follow-up visits by the PSVs, they perceived better ability to manage ACPs' pain and were motivated to apply the acquired knowledge, with ultimate control of ACPs' pain. There is contradicting evidence on the effects of the enhanced FCGs' SE for pain or symptom management on the ACPs' outcomes such as pain status, symptom-related distress, functional and physical well-being, and quality of life [25, 28, 36] and this may be attributed to the approaches used, intensity of the education interventions, and the outcome measures used [32, 33]. Among the FCGs of ACPs, reports of reduced depressive symptoms and anxiety amidst improved preparedness and SE for pain management after an education intervention exist [27]. In view of Bandura's conceptualization of SE [37], FCGs with high perceived SE are more likely to cope well with ACPs' pain management and sustain their efforts to control pain amidst challenges. Therefore, the findings of our study are very valuable when viewed within Bandura's perspective because cancer care within resource-limited settings, like Uganda, is very reliant on FCGs [38]. There is a need to restructure cancer care services in Uganda and similar settings to ensure integration of components focused on empowering FCGs of cancer patients in order to enhance the quality of cancer care and the well-being of both patients and their families.

The participants for the current study were only those FCGs who lived within 20 km of the catchment area of HAU and UCI; this limits the generalizability of the findings.

The study is also limited by the lack of randomization, lack of utilization of a control group, lack of patient outcome measures related to cancer pain, and scarcity of literature about interventions focusing on FCGs of ACPs and pain management delivered in the home setting. Despite its limitations, the current study highlights the potential utility of education interventions delivered in the home settings or as part of home care programs in resource-limited settings where the burden of cancer is on the rise and FCGs are in need of formal support in order to cope with the caregiving burden. The study also highlights the potential of home care and FCGs in enhancing cancer care and cancer pain management in resource-limited settings.

## Implications

The current study findings of improved FCGs' knowledge and self-efficacy for pain management provide insight into the needed way forward in order to enhance cancer care in resource-limited settings. The study informs us that the way forward may include improving home care programs for cancer patients and their FCGs, providing formal support to FCGs, partnering with FCGs and utilization of socially contextualized education interventions (peer support resource persons). The nurses can carefully integrate peer support and other supportive interventions that provide socially comprehensive knowledge and skills for pain and related symptom management in education interventions given to FCGs of ACPs during home visits. The follow-up support beyond the hospital setting is valuable and promotes continuity of cancer pain management. Follow-up support can be implemented through peer support volunteers who can easily serve as role models, providers of motivation, encouragement, and emotional comfort. The cost of such a social strategy in resource-limited settings like Uganda is a key factor, but the access and sustainability of such interventions need to be further studied.

## Conclusion

Pain is a highly ranked source of suffering among ACPs and their FCGs in Uganda. The current study utilized an education intervention for home management of cancer pain among ACPs delivered to FCGs in the home setting. The intervention led to improvements in FCGs' knowledge and SE for cancer pain management at home. Therefore, home-based FCG education interventions and home care programs at large should be considered as an important strategy that can be used to enhance cancer pain control in resource-limited settings such as Uganda.

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## Compliance with Ethical Standards

**Conflict of Interest** The authors declare that they have no conflict of interest.

**Research Involving Human Participants** All procedures performed in this study were in accordance with the ethical standards of the local institutional review boards and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

**Informed Consent** Prior to participation, all participants provided written informed consent.

## References

- International Agency for Research on Cancer (2013) Latest cancer statistics global cancer burden rises to 14.1 million new cases in 2012: marked increase in breast cancer must be addressed. Press release. <http://www.iarc.fr/en/media-centre/pr/2013/pdfs/pr223E.pdf>. Accessed 1 Jan 2018
- Stark L, Tofthagen C, Visovsky C, McMillan SC (2012) The symptom experience of patients with cancer. *J Hosp Palliat Nurs* 14:61–70
- 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](http://link.springer.com/chapter/10.1007/978-0-85729-230-8_2#page-1). Accessed 16 May 2018
- Valeberg BT, Grov EK (2013) Symptoms in the cancer patient – of importance for their caregivers’ quality of life and mental health? *Eur J Oncol Nurs* 17:46–51
- Harrington CB, Hansen JA, Moskowitz M, Todd BL, Feuerstein M (2010) It’s not over when it’s over: long term symptoms in cancer survivors- a systematic review. *Int J Psychiatry Med* 40:163–181
- Namukwaya E, Leng M, Downing J, Katabira E (2011) Cancer pain management in resource limited setting: A practice review. *Pain Res Treat*. <http://www.hindawi.com/journals/prt/2011/393404/abs>. Accessed 4 Jan 2018
- 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>
- 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
- Miaskowski C, Kragness L, Dibble S, Wallhagen M (1997) Differences in mood states, health status, and caregiver strain between family caregivers of oncology outpatients with and without cancer-related pain. *J Pain Symptom Manag* 13:138–143
- Ovayolu O, Ovayolu N, Aytac S, Serce S, Sevinc A (2015) Pain in cancer patients: pain assessment by patients and family caregivers and problems experienced by caregivers. *Support Care Cancer* 23:1857–1864
- Kelley M, Demiris G, Nguyen H, Olive DP, Wittenberg-Lyles E (2013) Informal hospice caregiver pain management concerns: a qualitative study. *Palliat Med* 27:673–682
- Swarm R, Abernethy AP, Angheluescu 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
- 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
- McPherson CJ, Hadjistavropoulos T, Lobchuk MM, Kilgour KN (2013) Cancer-related pain in older adults receiving palliative care: patient and family caregiver perspectives on the experience of pain. *Pain Res Manag* 18:293–300
- 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
- Gibson MJ, Kelly KA, Kaplan AK (2012) Family caregiving and transitional care: a critical review. Family caregiver alliance, San Francisco [https://caregiver.org/sites/caregiver.org/files/pdfs/FamCGing\\_TransCare\\_CritRvw\\_FINAL10.31.2012.pdf](https://caregiver.org/sites/caregiver.org/files/pdfs/FamCGing_TransCare_CritRvw_FINAL10.31.2012.pdf). Accessed 7 Feb 2018
- Kwom JH (2014) Overcoming barriers in cancer pain management. *J Clin Oncol* 32:1727–1733
- Northouse LL, Katapodi MC, Song L, Zhang L, Mood DW (2010) Interventions with family caregivers of cancer patients: meta-analysis of randomised trials. *CA Cancer J Clin* 60:317–339
- Orem J (2016) The state of oncology in Africa 2015. In: Boyle P, Ngoma T, Sullivan R et al. (eds). *iPRI*, Lyon. <https://i-pri.org/wp-content/uploads/2017/02/STATE-OF-ONCOLOGY-IN-AFRICA-2015-WEB-VERSION.pdf>. Accessed 5 July 2018
- Burki TK (2016) Radiotherapy challenges in Uganda. *Lancet Oncol* 17:e185. [https://doi.org/10.1016/S1470-2045\(16\)30059-6](https://doi.org/10.1016/S1470-2045(16)30059-6)
- Fraser BA, Powell RA, Mwangi-Powell FN, Namisango E, Hannon B, Zimmermann C, Rodin G (2017) Palliative care development in Africa: lessons from Uganda and Kenya. *J Global Oncol* 4:1–10
- Ferrell BR, Grant M, Borneman T, Juarez G, Veer AT (1999) Family caregiving in cancer pain management. *J Palliat Med* 2:185–195
- 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
- Katz S, Downs TD, Cash HR, Grotz RC (1970) Progress with development of the index of ADL. *Gerontologist* 10:20–30
- Cagle JG, Zimmerman S, Cohen LW, Porter LS, Hanson LC, Reed D (2015) EMPOWER: an intervention to address barriers to pain management in hospice. *J Pain Symptom Manag* 49:1–12
- 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
- Hendrix CC, Bailey DE Jr, Steinhauser KE, Olsen MK, Stechuchak KM, Lowman SG, Schwartz AJ, Riedel RF, Keefe FJ, Porter LS, Tulskey JA (2016) Effects of enhanced caregiver training program on cancer caregiver’s self-efficacy, preparedness, and psychological well-being. *Support Care Cancer* 24:327–336
- Vallerand AH, Hasenau SM, Templin T (2010) Improving cancer pain management in the home. *Advanced Cancer. Pain and Quality*

- of Life. <http://english.360elib.com/datu/R/EM380797.pdf#page=44>. Accessed 14 May 2018
29. Chen SC, Lai YH, Liao CT, Huang BS, Lin CY, Fan KH, Chang JTC (2014) Unmet supportive care needs and characteristics of family caregivers of patients with oral cancer after surgery. *Psycho-Oncology* 23:569–577
  30. 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
  31. McPherson CJ, Hadjistavropoulos T, Devereaux A, Lobchuk MM (2014) A qualitative investigation of the roles and perspectives of older patients with advanced cancer and their family caregivers in managing pain in the home. *BMC Palliat Care* 13:1–13
  32. Latter S, Hopkinson JB, Richardson A, Hughes JA, Lawson E, Edwards D (2016) How can we help family carers manage pain medicines for patients with advanced cancer? A systematic review of intervention studies. *BMJ Support Palliat Care* 6(3):263–275. <https://doi.org/10.1136/bmjspcare-2015-000958>
  33. Cummings GG, Olivo SA, Biondo PD, Stiles CR, Yurtseven O, Fainsinger RL, Hagen NA (2011) Effectiveness of knowledge translation interventions to improve cancer pain management. *J Pain Symptom Manag* 41:915–939
  34. Waldron EA, Janke AE, Bechtel CF, Ramirez M, Cohen A (2013) A systematic review of psychosocial interventions to improve cancer caregiver quality of life. *Psychooncology* 22:1200–1207
  35. Mahendran R, Lim HA, Tan JYS, Ng HY, Chua J, Lim SE, Kua EH, Griva K (2017) Evaluation of a brief pilot psychoeducational support group intervention for family caregivers of cancer patients: a quasi-experimental mixed-methods study. *Health Qual Life Outcomes* 15:17. <https://doi.org/10.1186/s12955-017-0595-y>.
  36. Bilgin S, Gozum S (2016) Effect of nursing care given at home on the quality of life of patients with stomach cancer and their family caregivers' nursing care. *Eur J Cancer Care* 27:1–11. <https://doi.org/10.1111/ecc.12567>
  37. Bandura A (1977) Analysis of self-efficacy theory for behavioral change. *Cogn Ther Res* 1:287–310
  38. Muliira JK, Kizza IB, Nakitende G (2018) Roles of family caregivers and perceived burden when caring for hospitalized adult cancer patients: perspective from a low-income country. *Cancer Nurs*. <https://doi.org/10.1097/NCC.0000000000000591>