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## **Extension for Community Healthcare Outcomes-Palliative Care in Africa Program: Improving Access to Quality Palliative Care**

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# Extension for Community Healthcare Outcomes-Palliative Care in Africa Program: Improving Access to Quality Palliative Care

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**PURPOSE** There is limited access to quality palliative care (PC) for patients with advanced cancer in sub-Saharan Africa. Our aim was to describe the development of the Project Extension for Community Healthcare Outcomes-Palliative Care in Africa (ECHO-PACA) program and describe a preliminary evaluation of attitudes and knowledge of participants regarding the ability of the program to deliver quality PC.

**METHODS** An interdisciplinary team at the MD Anderson Cancer Center, guided by experts in PC in sub-Saharan Africa, adapted a standardized curriculum based on PC needs in the region. Participants were then recruited, and monthly telementoring sessions were held for 16 months. The monthly telementoring sessions consisted of case presentations, discussions, and didactic lectures. Program participants came from 14 clinics and teaching hospitals in Ghana, Kenya, Nigeria, South Africa, and Zambia. Participants were surveyed at the beginning, midpoint, and end of the 16-month program to evaluate changes in attitudes and knowledge of PC.

**RESULTS** The median number of participants per session was 30. Thirty-three (83%) of 40 initial participants completed the feedback survey. Health care providers' self-reported confidence in providing PC increased with participation in the Project ECHO-PACA clinic. There was significant improvement in the participants' attitudes and knowledge, especially in titrating opioids for pain control ( $P = .042$ ), appropriate use of non-opioid analgesics ( $P = .012$ ), and identifying and addressing communication issues related to end-of-life care ( $P = .014$ ).

**CONCLUSION** Project ECHO-PACA was a successful approach for disseminating knowledge about PC. The participants were adherent to ECHO PACA clinics and the completion of feedback surveys. Future studies should evaluate the impact of Project ECHO-PACA on changes in provider practice as well as patient outcomes.

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## INTRODUCTION

Patients with advanced cancer frequently experience significant physical and psychosocial distress, functional decline, and spiritual and financial concerns.<sup>1,2</sup> These patients often have complex communication and decision-making needs throughout their disease trajectory that also have a negative impact on their quality of life.<sup>3</sup> Access to quality palliative care (PC), especially earlier in the disease trajectory, has been shown to improve health-related quality of life, mood, and quality of end-of-life care in these patients.<sup>4,5</sup> In sub-Saharan Africa, at least 2 million patients need end-of-life PC at any given time. Moreover, the need for PC in Africa is increasing, and more than 800,000 new cancer cases require PC.<sup>6-10</sup> However, less than 15% of all patients who need PC in sub-Saharan Africa currently have access to this critical service. Barriers to accessing PC in sub-Saharan Africa include insufficient knowledge of PC among health care providers and an extreme shortage of PC specialists in the

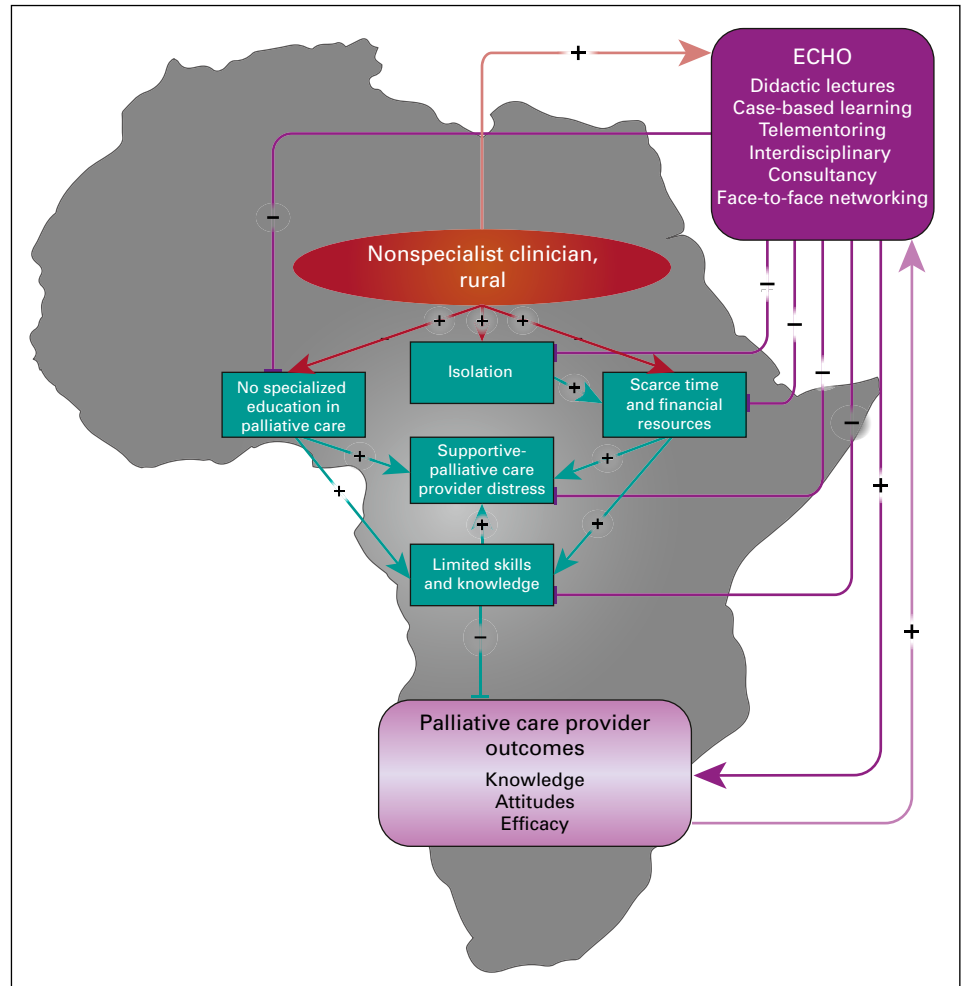
region.<sup>7,11-14</sup> Among patients with advanced cancer in sub-Saharan Africa, additional barriers also contribute to limited access to PC, such as little or no financing framework for PC to integrate with other health care financing mechanisms, rudimentary PC policies and data frameworks, lack of access to oral morphine or other PC medications, legal barriers regarding administration of opioids, and significant geographic distance between patients and PC services.<sup>6,9,11,15-19</sup>

Several factors contribute to the limited knowledge of PC among those who provide care for patients with advanced cancer,<sup>20</sup> including scarcity of time and financial resources, lack of access to specialized education, and isolation from other PC providers.<sup>21-23</sup> An innovative intervention, Project Extension for Community Healthcare Outcomes-Palliative Care in Africa (Project ECHO-PACA), was started in May 2016 to alleviate these problems and improve the capacity to provide quality PC (Figure 1). This program was based on the ECHO model, an established telementoring and

Author affiliations and support information (if applicable) appear at the end of this article.

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**FIG 1.** Conceptual model of the Project Extension for Community Healthcare Outcomes - Palliative Care Africa (Project ECHO-PACA) program. The figure depicts some of the unique challenges faced by primary care clinicians (red) in rural/underserved regions when developing their knowledge and skills in palliative care (green), and the anticipated benefits of Project ECHO-PACA. Novel and cost-effective ECHO telementoring sessions (purple) will educate participants on the principles of palliative care, best practices, and application of palliative care concepts, benefiting these providers who deliver primary palliative care to underserved communities.



support program.<sup>24-27</sup> The goal of this innovative project was to improve access to PC by offering cost-effective training and providing updates in the principles of PC, best practices, and application of PC concepts for the providers who deliver primary PC to underserved communities. The aim of this article is to describe the development of the program and a preliminary survey of attitudes and knowledge of those who participated in a Project ECHO-PACA clinic regarding delivery of quality PC.

## METHODS

### Leveraging ECHO Methodology for PC in Africa

Project ECHO was conceived at the University of New Mexico in 2003 by a team led by Sanjeev Arora, MD, to fill an unmet need for high-quality care for rural patients in New Mexico who had hepatitis C and who lacked access to specialist-level care providers.<sup>24,26</sup> The mission of the initial Project ECHO was to improve the capacity of the primary care providers in rural and underserved areas of the state to follow best practices in providing specialty care similar to that available in the university setting. It follows a hub-and-spokes model in that a hub of experts train distant

providers (spokes) through a telementoring platform that includes didactic education, case presentation, and group discussion.<sup>28</sup> The model is centered on case-based learning similar to that provided in specialist residency education. At the core of Project ECHO is a user-friendly, free teleconferencing technology (Zoom) that participants can access from any Internet-connected smartphone, tablet, laptop, or personal computer using the speakers, cameras, and microphones integrated into these devices. Thus, participants can connect to Project ECHO sessions from almost any Internet-equipped location. The ECHO model differs from traditional telemedicine, in which a single patient is diagnosed and treated through videoconferencing technology. In Project ECHO, the participants are trained to provide specialist-level care to all their patients, thus multiplying the effect of the educational intervention and effectively turning generalist practitioners into specialists. It also differs from other forms of Internet-based education (such as watching videos or webinars) because the technology brings the hub specialists and all spoke participants together to interact and discuss their most difficult cases, thus enhancing participants' level of

learning. The model is unique in that it can be improved over the course of the intervention period to obtain best outcomes by using feedback from various stakeholders such as patients, regional collaborators, and the interdisciplinary team at the hub.

Since its inception, the reach of Project ECHO has expanded beyond New Mexico and the United States<sup>25,27</sup> and has addressed a multitude of conditions beyond hepatitis C.<sup>29-36</sup> Project ECHO has been used to successfully educate primary care clinicians in treating both chronic and acute diseases worldwide by effectively expanding patient access to specialist care and by disseminating knowledge and experience regarding PC to specialists.<sup>25,27</sup>

The importance of validating ECHO's role in expanding access to quality health care was prioritized by the federal government when the ECHO Act of 2016 was signed into law. Indeed, participants have reported that their participation in Project ECHO is valuable to their practice on many levels. Positive outcomes for patients have also been reported,<sup>29-36</sup> and in the case of hepatitis C, outcomes of the care provided by ECHO-trained, rural primary care clinicians rivaled that of academic medical center specialists.<sup>24</sup> A meta-analysis of publications that investigated Project ECHO concluded that it can be a cost-effective means of improving both provider competence and patient outcomes.<sup>27</sup> Thus, on the basis of these positive outcomes and the previous experience of our team at The University of Texas MD Anderson Cancer Center (MDACC) in preventing cervical cancer,<sup>25</sup> we hypothesized that the innovative use of this cost-effective ECHO platform would improve access to education and thereby advance best practices in PC in underserved areas of sub-Saharan Africa.<sup>22</sup> The mission of the MDACC Global Academic Program is to work collaboratively with other cancer centers (eg, Sister Institution Network) to end cancer. In working with Pink Ribbon Red Ribbon (a partnership focused on women's cancers in low- and middle-income countries whose initial focus was on cervical and breast cancers in Zambia, Tanzania, Ethiopia, and Mozambique) and other partner institutions in Africa, our MDACC team identified several unmet needs among patients receiving cancer care in sub-Saharan Africa. One of the most important needs was increased capacity to provide PC in underserved communities. This was a result of the fact that a majority of patients have difficulty obtaining timely cancer prevention, treatment, symptom control, and end-of-life care because of limited resources and lack of trained personnel, among the other barriers. Therefore, to optimize cancer care in this region, we established a pilot project with collaboration between MDACC, University of New Mexico, and various cancer institutions in Africa to improve access to quality PC in sub-Saharan Africa. On the basis of emerging evidence, we hypothesized that improving capacity to provide PC would not only improve patient quality of life but would also facilitate quality cancer care and thereby mitigate the

devastating effects of cancer. We also anticipated additional benefits. This project was funded by a grant from the University Cancer Foundation, Sister Institution Cancer Fund.

### Identification of Faculty and Participants

PC leaders from the African Palliative Care Association and various cancer centers in Africa were approached. These PC leaders were involved in selecting the Project ECHO partners (spokes) in Ghana, Zambia, Kenya, Nigeria, Tanzania, and South Africa on the basis of their PC needs and ease of access to the Internet/Zoom platform.

Volunteer faculty, which included academic physicians and nurses from Kenya, Nigeria, and Ghana who were interested in Project ECHO, were originally recruited on the basis of their previous experience teaching about quality PC in the original participant (spoke) countries. They understood the local needs and were thus able to facilitate curriculum development. In addition, academic faculty from the United States, England, and Brazil with previous experience in teaching in rural and underserved areas in African countries were included.

The goal of the curriculum was to convey up-to-date advances in PC to care providers so they could use best practices in PC. The core of the curriculum was based on the PC curriculum at MDACC, which included provision of current principles of PC, best practices for management of symptoms (including pain), skills necessary for excellent patient-clinician communication (including discussion of end-of-life issues), and prognostication of survival. Input from local experts led to refinement of the curriculum based on the local needs and available resources. As Project ECHO progressed and additional needs came to light, the curriculum was further revised to fill gaps in the PC needs identified by participant assessments performed after each Project ECHO clinic session. On the basis of input from local experts, the following topics were added: case-based discussion of opioid titrations, wound care in malignant head and neck cancers, management of mucositis, management of adverse effects of chemotherapy, nutrition at the end of life, communicating with community physicians about when referral is appropriate, management of end-stage renal failure in patients with cervical cancer, and management of refractory dyspnea in the community setting.

The feedback survey was prepared using the Moore's Expanded Outcomes Framework for assessing learners and evaluating instructional activities.<sup>37</sup> Similar surveys were used by previous Project ECHO teams for various other disease states, as well as in educational projects in low- and middle-income countries to assess learners and evaluate instructional activities.<sup>24,27</sup> We evaluated participation rate as well as participant satisfaction and declarative knowledge gained as a result of participation in Project ECHO. On the basis of this preliminary data, future controlled studies are needed to assess provider competence, performance, impact on patient-reported outcomes, and community health.

### Assessments of the Project ECHO-PACA Clinic Sessions (feedback surveys)

Monthly Project ECHO-PACA telementoring sessions consisting of case presentations, discussions, and didactic lectures started in July 2016. Program participants came from 14 clinics and teaching hospitals in Ghana, Kenya, Nigeria, South Africa, and Zambia. Participants were surveyed at the beginning, midpoint, and end of the 16-month program to evaluate changes in attitudes, knowledge, and self-perceived efficacy in assessing and managing pain, identifying signs and symptoms of imminent death, and identifying and addressing challenging communication issues related to the end of life. Table 1 provides the checklist of activities before, during, and after the monthly Project ECHO-PACA clinics.

#### Statistical Analysis

We summarized the data using descriptive statistics, including medians, interquartile ranges, and frequencies. Categorical variables were summarized by using percentages and frequencies, and differences were analyzed using a two-sided  $\chi^2$ /Fisher's exact test. Because this was a pilot study, a convenient sample size was used and no formal sample

size calculation was made.  $P < .05$  was considered to be statistically significant. SPSS version 19.0 (SPSS, Chicago, IL) was used for statistical analysis.

### RESULTS

Table 2 provides the demographic characteristics of the spoke participants in Project ECHO-PACA. The median number of participants per session was 30. The median duration of monthly meetings was 90 minutes.

After the monthly Project ECHO-PACA clinic meetings, a survey of participants was conducted using a 5-point, fully word-anchored, balanced bipolar scale. On average, 39 participants (97%) reported being either extremely or quite satisfied with the Project ECHO-PACA clinics, 39 (97%) reported that the faculty lecturer for the didactic sessions was either extremely skilled or very skilled in the subject matter, and 33 (91.7%) reported that the case discussion during the Project ECHO-PACA clinic was extremely useful or quite useful. All participants reported that they were likely to apply what they learned at the Project ECHO-PACA meeting to their PC practice, and all agreed to participate in the future Project ECHO-PACA clinics.

**TABLE 1.** Logistics of the Project ECHO-PACA Clinic

Timing Relative to the Clinic	Activity
Before	Schedule room and information technology support
Before	Create clinic in iECHO
Before	Create meeting in calendar
Before	Send first invitation to ECHO clinic (first Thursday of the month)
Before	Send second invitation to ECHO clinic (second Thursday of the month)
Before	Send third invitation to ECHO clinic (third Thursday of the month)
Before	Send fourth invitation to ECHO clinic (Monday of clinic week)
Before	Get electronic copy of the didactic presentation from the assigned speaker
Before	Finalize cases to be presented (Monday of clinic week)
Before	Send case to participants
Before	Send final invitation to ECHO clinic (morning of the clinic)
Before	Print attendance sheet (Wednesday before clinic)
Before	Bring electronic copy of didactic presentation (Thursday of in-person or online meeting)
Before	Update attendance list on global e-mail list
Before	Add new guests if necessary
During	Take attendance
During	Video record clinic
After	Mark clinic as complete in iECHO
After	Watch video to complete attendance list
After	Send thank you e-mail to everyone and ask attendees to verify attendance
After	Update attendance sheet in Microsoft Excel and in iECHO
After	Add didactic and case presentations to iECHO

NOTE. iECHO is Web-based and is used to manage and audit ECHO clinics, collect data on ECHO clinic performance, and provide online resources to ECHO clinic participants.

Abbreviation: ECHO-PACA, Extension of Community Health Outcomes-Palliative Care in Africa.

**TABLE 2.** Demographic Characteristics of Project ECHO-PACA Participants (N = 40)

Characteristic	Frequency	%
Female sex	26	70
Highest level of education		
College	7	17.5
Post college	9	22.5
Advanced degree	24	60.0
Years of employment in health care		
6 months to 1 year	1	2.5
1-3 years	2	5
3-5 years	3	7.5
5-10 years	12	30.0
10-20 years	13	32.5
> 20 years	9	22.5
Experience in palliative care		
6 months to 1 year	3	7.7
1-3 years	13	33.3
3-5 years	8	20.5
5-10 years	10	25.6
10-20 years	3	7.7
> 20 years	2	5.1
Did not answer	1	2.6
Type of training		
Administrator	1	2.6
Dietician	1	2.6
Nurse	15	38.5
Pharmacist	2	5.1
Physician	17	43.6
Psychologist	2	5.1
Social worker	1	2.6
Did not answer	1	2.6
Current clinical role		
Administrator	2	5.0
Dietician	1	2.5
Nurse	12	30.0
Pharmacist	2	5.0
Physician	15	37.5
Psychologist	2	5.0
Social worker	3	7.5
Did not answer	3	7.5

Abbreviation: ECHO-PACA, Extension of Community Health Outcomes-Palliative Care in Africa.

Thirty-three of 40 initial participants (83%) completed the feedback survey at pretest 1, post-test 1, and post-test 2 (Table 3). Seven participants (17%) were unable to complete the three surveys because of attrition. Providers' self-reported confidence in providing PC increased with

participation in the Project ECHO-PACA clinic. There was significant improvement in the participants' attitudes and knowledge in the following topics because the faculty lecturer was reported as being either well prepared or very well prepared on a 5-point fully word-anchored balanced bipolar scale. The topics included titrating opioids for pain control ( $P = .042$ ), appropriate use of non-opioid analgesics ( $P = .012$ ), and identifying and addressing communication issues related to end-of-life care ( $P = .014$ ; Table 3). The participants with less than 5 years of experience in PC showed a significant improvement in titrating opioids for optimization of pain control ( $P = .01$ ), and training as a nurse was associated with improvement in appropriate use of non-opioid analgesics ( $P = .05$ ) and identifying signs and symptoms of imminent death ( $P = .06$ ).

## DISCUSSION

There is a great need to improve access to quality PC in underserved areas of Africa. One critical area for improvement is enhancing knowledge of how to provide quality PC among health care providers who care for patients with advanced cancer. Thus, the objective of this project was to establish an innovative, cost-effective tele-mentoring program (Project ECHO-PACA) designed to educate providers and increase the capacity to provide quality PC in sub-Saharan Africa. We described the establishment of Project ECHO-PACA and provided preliminary data regarding the results of the survey on the attitudes and knowledge of the providers who participated in the project. We found that this Project ECHO-PACA pilot was a successful program and was a pragmatic approach to improving knowledge of PC without the need for travel. Thus, Project ECHO-PACA has the potential to increase access to quality PC by enhancing the skills of providers in resource-challenged areas of sub-Saharan Africa.

Because the instructional strategy for Project ECHO-PACA had already been validated,<sup>24,27,28</sup> the key steps to meeting our objective were to identify the spokes that would represent the communities needed to address PC needs, establish collaboration and facilitate connectivity between these spokes and the central hub, and develop the curriculum based on provision of quality PC and characteristics and needs of the patient population. One of the important goals of Project ECHO-PACA, which we met, was to complete the curriculum and assess the attitudes and knowledge of providers throughout the process. This would become the first ECHO project of this kind, conducted in various international centers that provide PC for patients with cancer, to be published. One of the important things we learned from this project was that to replicate Project ECHO-PACA (ie, to reach out to the primary care providers in community), we first had to reach out to the key stakeholders of PC programs in individual African countries (see Methods under Identification of Faculty and Participants). A second important aspect for the success of

**TABLE 3.** Change in Attitudes and Knowledge of Participants in the Project ECHO-PACA Clinic (N = 33)

Item	Pretest %	Post-Test 1%	Post-Test 2%	P*
Very well or well prepared for:†				
Assessing pain etiology or causes	73	83	88	.50
Appropriate use of opioid analgesics for persistent pain	73	75	92	.19
Titrating opioids to optimize pain control	46	74	87	.042‡
Appropriate use of non-opioid analgesics	70	82	100	.012‡
Interventional pain procedures	40	26	22	.59
Dose conversions of oral to parenteral opioids	56	46	41	.78
Managing procedural and postoperative pain	75	59	67	.85
Treating bone pain/neuropathic pain	44	64	73	.35
Recognizing and treating opioid withdrawal symptoms	56	62	46	.50
Identifying addiction behaviors	44	52	60	.70
Dose conversions of oral opioid analgesics	44	57	68	.46
Managing somnolence (drowsiness) and other associated effects of opioids	44	50	70	.26
Describing palliative care interventions	63	55	84	.067
Evaluating all limitations due to pain	40	59	69	.27
Assessing functional limitations and impairments	38	50	65	.23
Identifying signs/symptoms of imminent death	54	59	87	.053
Identifying and addressing challenging communication issues related to end of life	54	68	92	.014‡

NOTE. Project ECHO-PACA participants in percent (%) surveyed at the beginning (Pretest), mid-point (Post-Test 1), and end of the 16-month program (Post-Test 2), to evaluate changes in attitudes and palliative care knowledge.

Abbreviation: ECHO-PACA, Extension of Community Health Outcomes-Palliative Care in Africa.

\*A 5-point fully word anchored balanced bipolar scale with responses of not well prepared, well prepared, somewhat prepared, well prepared, and very well prepared was used.

†Term used to describe the level of preparation of the clinic facilitator in the areas listed.

‡Statistically significant.

Project ECHO-PACA was to develop curriculum and best practices based on local PC needs. We promoted active collaboration among the regional PC experts and gathered input from the primary care providers. A third critical aspect for the success of Project ECHO-PACA was proactive collaboration in establishing the Internet link (Zoom), and actively troubleshooting if connecting became a problem.

In this article, we have described the development and establishment of Project ECHO-PACA. We found that the program was well received, with a median participation of 75% over 16 months. We conducted feedback surveys at the beginning, midpoint, and end of the program to determine trends toward improving providers' self-reported confidence in providing PC. Confidence increased with participation in the Project ECHO-PACA clinic, especially in titrating opioids for pain control, using non-opioid analgesics appropriately, and identifying and addressing communication issues related to end-of-life care. However, no research was conducted to examine improvement in participants' practices in providing quality PC and improvement of patient and caregiver outcomes. Future studies should build on the current success of the program to evaluate the effectiveness of Project ECHO-PACA in improving best practices

in PC and improving patient and caregiver outcomes in quality of life, symptoms, and satisfaction with care. Ultimately, studies are also needed to evaluate the effect on health care systems as a whole.

In the analysis of the feedback survey, certain components such as "dose conversions of oral to parenteral opioids" revealed a drop in the percentage of improvement from pretest to post-test. The reasons for this decrease were not clear, but the pilot nature of the study and small sample size could have had an effect. They may indicate a change in the participants' perception of self-assessment of knowledge regarding quality PC rather than actual improvement in the content. In addition, because of the small sample size of the survey, it was not clear why certain components of the survey such as "evaluation of [activities of daily living] limitations due to pain" and "addressing functional limitations and impairments" were not significant in terms of change in the post-test despite being basic and important parts of the assessment of PC. Additional studies are needed to qualitatively evaluate the reasons for these variations, evaluate a revised curriculum, and perhaps provide a booklet with more emphasis on these components.



Project ECHO-PACA was a successful program that represented a pragmatic approach to disseminating knowledge of PC without the need for travel. Based on the success of the pilot phase, Project ECHO-PACA has the potential to improve access to quality PC by

enhancing the skills of providers in resource-challenged areas of sub-Saharan Africa. Future studies need to evaluate the impact of Project ECHO-PACA on changes in provider practice and on patient outcomes.

## AFFILIATIONS

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### AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST AND DATA AVAILABILITY STATEMENT

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Relationships are self-held unless noted. I = Immediate Family Member, Inst = My Institution. Relationships may not relate to the subject matter of this manuscript. For more information about ASCO's conflict of interest policy, please refer to [www.asco.org/rwc](http://www.asco.org/rwc) or [ascopubs.org/jgo/site/misc/authors.html](http://ascopubs.org/jgo/site/misc/authors.html).

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