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Special Article

The Palliative Care—Promoting Access and Improvement of the Cancer Experience (PC-PAICE) Project in India: A Multisite International Quality Improvement Collaborative

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Abstract

Mentors at seven U.S. and Australian academic institutions initially partnered with seven leading Indian academic palliative care and cancer centers in 2017 to undertake a program combining remote and in-person mentorship, didactic instruction, and project-based learning in quality improvement (QI). From its inception in 2017 to 2020, the Palliative Care—Promoting Accesst and Improvement of the Cancer Experience Program conducted three cohorts for capacity building of 22 Indian palliative care and cancer programs. Indian leadership established a Mumbai QI training hub in 2019 with philanthropic support. In 2020, the project which is now named Enable Quality, Improve Patient care - India (EQuIP-India) focuses on both palliative care and cancer teams. EQuIP-India now leads ongoing Indian national collaboratives and training in QI and is integrated into India's National Cancer Grid. Palliative Care—Promoting Accesst and Improvement of the Cancer Experience demonstrates a feasible model of international collaboration and capacity building in palliative care and cancer QI. It is one of the several networked and blended learning approaches with potential for rapid scaling of evidence-based practices. J Pain Symptom Manage 2021;61:190–197. *Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine.*

Key Words

Quality improvement, India, U.S., Australia, cancer, palliative care

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Key Message

Palliative Care—Promoting Access and Improvement of the Cancer Experience demonstrates a feasible model of international collaboration and capacity building in palliative care and cancer quality improvement.

Introduction

The Challenge of Aging and Serious Chronic Illness in India

Chronic disease has become the most rapidly growing health scourge, and an important underlying risk for aging adults worldwide, as demonstrated more recently by the impact of the coronavirus disease 2019 (COVID-19) pandemic. Noncommunicable disease accounts for most of the global disease burden with the number of persons affected by noncommunicable diseases continuing to grow. Chronic illnesses particularly impact older adults, causing extensive human suffering and burdening health systems. Globally in 2015, the Lancet Commission found that about 61 million persons were living with and 25 million persons died with conditions for which palliative care may be helpful, and that palliative care can relieve suffering at a generally acceptable social cost.[1]

India faces one of the largest global challenges in responding to these unmet needs for palliative services and supports for older adults. With a population of nearly 1.5 billion, 103.8 million are currently older than 65 years, of whom 8% are bedbound or housebound. India has more older adults than any country other than China, a total that is projected to grow to more than 300 million in 2050.[2–4] Population aging will be accompanied by more Indians living with cancer and other serious conditions. By 2020, Indian population-based cancer registries project an increase of about 400,000 new cases to nearly 1.7 million incident cancer cases annually.[5] The COVID-19 outbreak demonstrates high mortality in age and disease risk groups, underscoring the urgency of meeting supportive needs in older and sicker persons.[6]

The human toll on older Indian adults and families is substantial.[7] Among middle-class Indians, health care use at the end of life appears to be increasing and is often associated with financial hardship. Despite increasing national wealth, only Nigeria has a greater number of citizens than India living on less than $1.25/day, the global standard for extreme poverty.[8] Nearly 20% of all Indian suicides are associated with serious illness.[9] Opioid availability remains very constrained despite reforms to India's major opioid control law in 2014.[10] In addition to pain management, this raises concern about currently available palliation for dyspnea.

The Indian health system relies on both public and private payments, and services for aging adults, including palliative care, are in short supply in both private and government sectors. Access to health care is exacerbated by barriers to accessing free government care; out-of-pocket costs comprise nearly 70% of Indian health care spending.[3] Palliative care services are concentrated in population centers, and less than 1% of India's population has geographic access to palliative care.[11,12] Nearly two-thirds of palliative care services are located in the state of Kerala, where only 3% of India's population resides.[13]

However, in India, there is increasing attention to the need for palliative care, particularly among patients with cancer.[4] India recently established a National Cancer Grid (NCG) in 2012 to encourage standards for uniform service delivery and promote high-quality oncology care.[14] A recent national universal health insurance scheme (i.e., Ayushman Bharat) promises modest support for the provision of palliative care.[15] Both India's profound need and recent promising momentum have strongly influenced the rationale for and development of the Palliative Care—Promoting Access and Improvement of the Cancer Experience (PC-PAICE) Project.

This report describes the development and conduct of PC-PAICE in the context of Cohort 1 and progress and changes instituted for subsequent cohorts.

The PC-PAICE Project

The PC-PAICE Project originated after discussion with palliative care leaders gathered in Coimbatore, India, for the 2017 Indian Palliative Care Conference (IAPCON 2017). We developed PC-PAICE to foster collaborative learning and quality improvement (QI) education among an initial cohort of seven leading Indian palliative care programs based in major academic and community centers. Each Indian team partnered with one or more coaches at peer institutions with palliative care cancer services in the U.S. or Australia (Table 1: PC-PAICE 2018 cohort description).

The educational content of PC-PAICE was adapted from the Realizing Improvement through Team Empowerment (RITE) and Clinical Excellence Leadership Training curricula, both established QI training programs at Stanford University School of Medicine that combine didactic instruction with a mentored QI project.[16] Stanford team leaders for PC-PAICE included an academic and palliative care content leader (K. A. L.) and two Stanford organizational and QI leaders (J. M. and M. D.). Our QI leaders (J.

Table 1
PC-PAICE 2018 Cohort Description

Indian QI Sites 2017–2018	Project Goal	U.S. and Australian Mentor Sites
All India Institute of Medical Sciences, New Delhi	Decrease the time between registration at head & neck cancer clinic and referral to palliative medicine for patients with advanced oral cancer from an average of 50 days to 10 days	Stanford University, Stanford, CA
CIPLA Palliative Care Center, Pune, Maharashtra	Achieve an increase from 0% to 30% of accepted referrals of patients with solid tumors who are receiving anticancer treatment with curative intent from Indrayani Hospital	Peter MacCallum Cancer Center, Melbourne, Victoria
Homi Bhaba Cancer and Research Center, Andhra Pradesh	Increase the number of home visits for patients in need from two to three per week to at least six per week by June 2018	Duke Univeristy, Durham, NC
MNJ Institute of Oncology Regional Cancer Center, Hyderabad, Telangana	Improve coordination and transmission of patient goals of care, from hospital to hospice providers, from 1.5 to 5 (on a 0–10 rating confidence score as graded by the hospice doctor)	University of California San Francisco, San Francisco, CA
Tata Memorial Center, Mumbai, Maharashtra	Increase referral of outpatients with Stage IV nonsmall cell lung cancer and ECOG status 0–2, planned for palliative chemotherapy/targeted therapy to 75% for early palliative care	Johns Hopkins University, Baltimore, MD
Thrissur Institute of Palliative Care, Thrissur, Kerala	Document discussion of prognostication in 75% of the newly registered patients with cancer and/or the principal family members, within a span of five months	University of Technology, Sydney, New South Wales
Trivandrum Institute of Palliative Sciences, Thiruvananthapuram, Kerala	Increase the satisfaction score for the quality of delivered care to our patients: of doctors from 5.3 to 7.5 and of nurses from 6.2 to 8.0	Stanford University, Stanford, CA

PC-PAICE = Palliative Care—Promoting Access and Improvement of the Cancer Experience; QI = quality improvement; ECOG = Eastern Cooperative Oncology Group.

M. and M. D.) previously helped develop and lead multiple QI learning cohorts within Stanford School of Medicine and the Stanford Healthcare System.

There were specific criteria for PC-PAICE participation at the outset. Each Indian QI team identified a clinical leader and an organizational partner who could facilitate the time, resources, and other contextual factors necessary to undertake a QI project and act as local champions. Both the Indian teams and international coaches participated monthly in an hour-long and large group call for didactic instruction and problem solving. Indian sites and coaches scheduled at least one monthly individualized session for additional learning and problem solving. Almost all teams adhered to this schedule, and some teams met more frequently.

Indian teams represented institutions with established palliative care clinical services and academics. Indian team leaders of this pilot QI program were pioneers in the field of palliative care in India. PC-PAICE coaches included multidisciplinary palliative care physicians, nurses, and a pharmacist who had leadership roles in palliative care programs and experience working with patients with cancer in academic cancer centers in the U.S. and Australia. All coaches were knowledgeable about QI methods and had led QI at local, regional, or national levels. The coaches contributed diverse perspectives on working successfully in complex health care organizations. Many coaches had conducted research in or taught quality measurement and QI methods, and this abetted our approach of melding QI with evidence where possible.

The Approach, Resources, and Curriculum of PC-PAICE

Our educational approach was rooted in regular team interactions and structured to engage managers, frontline clinicians, and staff with relevant content to

build sustainable skills in QI. We reviewed project progress using a structured cadence, paralleling the didactic content and instruction used in general problem-solving methods.[16] Although there is mixed evidence supporting the collaborative model of QI,[17] the fundamental characteristics of PC-PAICE, including its team structure, didactic elements, user-driven access to resources, and practical, project focus, are aligned broadly with adult learning principles and the lessons learned from collaboratives in diverse international contexts.[18]

PC-PAICE expanded on general collaborative principles by embracing where possible the concept of evidence-based quality improvement (EBQI). Typical effectiveness studies focus on intervention and ignore context, and many QI approaches (e.g., Plan-Do-Study-Act) emphasize naturalistic methods, whereas EBQI engages evidence along the steps of a QI process. EBQI has been used to spread evidence-based practices for depression management, pressure ulcer reduction, and to improve antipsychotic prescribing.[19–21] Limited resources prevented fully operationalizing an EBQI approach in our initial cohorts; however, we emphasized context and stakeholder dialogue in team building and engaged clinician researchers as coaches.

Our communication platform for PC-PAICE allowed flexible access to resources, facilitated team and group communications, and could be coordinated across the diverse time zones of participants. All participants were given free access to file-sharing accounts at the outset. This allowed uploading and sharing core documents, agendas, meeting notes, supplementary articles, and instructional materials. We used a videoconference line for large group team meetings. This allowed the use of slides and screen sharing for didactics. Many team members used the video feature, which we perceived to strengthen interpersonal interactions.

To track and manage QI projects in PC-PAICE, we used the A3 template derived from industrial Lean management. The term A3 generally connotes the paper size (11.7″ × 16.5″) and is used as a shorthand term for a problem-solving guide that typically includes the sections of project title, problem statement, background, target state (SMART goal), current state identify target/actual/gap, analysis, key drivers, interventions/countermeasures, and sustain plan. In a broad sense, the A3 template aligned with both the curriculum and the project goals stressed during the course of PC-PAICE. Our project goal for more than six months was for each team to complete one mentored QI cycle in the course of their didactic instruction.

To mitigate distance challenges, we included a midcourse, all-day workshop, which was held for Cohort 1 in New Delhi during the national palliative care (IAPCON 2018) meeting. The workshop reinforced relationships between coaches and QI sites. We reviewed lessons learned, focused on problem solving, offered one-on-one mentorship from the leadership team, and emphasized the transition between understanding root causes and intervention. We also pruned the formal curriculum and meetings to the most essential content, adapted curriculum to emerging learner needs, and minimized the frequency and inconvenience of meetings to early or late in the workday, which the project's vast geographic scale required (Table 2: PC-PAICE curriculum overview).

Conducting an International QI Collaborative

The QI curriculum and tools were taught alongside projects. The timing of the content, offered in large-group didactics and individual team coaching sessions, was based on the sequential project challenges teams would be facing. During the first few months, teams were taught the importance of data collection and scoping their problem realistically. We emphasized a common QI language by using the A3 structure for problem solving. We taught standard tools such as key driver diagrams, run chart templates, and cause and effect diagrams to facilitate quick understanding of projects' current states and challenges. During final months, topics such as intervention reliability and sustain plans were discussed to assist teams in overcoming the common vulnerabilities of QI work such as interventions ceasing when team members move on.[22]

With regard to our large group monthly calls, following introductions and roll call, we prioritized team case presentation and problem solving for one to two teams during each call. We followed this with compressed didactic instruction using slides that were archived and remotely accessible to allow PC-PAICE participants (including those who missed specific calls) to subsequently view or review the materials. We shared the Stanford RITE videos, which could be freely accessed on YouTube to reinforce and extend the learning of each instructional session. Although we did not have resources to adapt them to the Indian context, these videos offer detailed information about the specific methods and tools of QI and generic examples of how to apply them.

At the beginning, the projects progressed at similar rates; all seven teams completing the problem statement and SMART goal alignment in the first two months. As teams engaged in root cause analysis and the testing of interventions, project progress varied. By the end of the fourth month, all QI teams had performed a root cause analysis. By the end of the six-month collaborative, all QI teams showed at least

Table 2
PC-PAICE Monthly Didactic Content and Objectives

Timeline	Learning Objective	Collaborative Details
Month 1	Prework—building the collaborative	All teams confirmed with mentors. Project charters filled out with proposals. Collaborative learning sessions, site visit, and graduation scheduled
Month 2	Introduction to A3 thinking and team roles	Videoconference covering problem statements, SMART goals, and run chart measurement
Month 3	Understanding the current state and root causes	One-day onsite workshop. Topics to include: current state analysis (fishbone, Pareto), process observation, outcome and process measures
Month 4	Key drivers and intervention identification	Videoconference covering key driver diagrams and intervention testing
Month 5[a]	Reliability of interventions and measures	Videoconference covering reliability levels. Time spent on run chart review
Month 6	Sustain plan development	Videoconference covering sustain plan development and intervention reliability
Month 7	Graduation presentation and closing	All teams present final project results and share key learnings from the collaborative. Publications and write-ups are considered and organized

PC-PAICE = Palliative Care—Promoting Access and Improvement of the Cancer Experience.
[a]All sessions were remote, and an all-day workshop at Indian Palliative Care Conference is held at approximately Months 2–3 to reinforce and expand on early learnings, foster team building, and engage in problem solving.

modest improvement in their chosen measure, four of the seven meeting the goal determined at the beginning of the collaborative, the remaining three teams seeing at least some improvement in their chosen primary measures.

Learner and Coach Feedback About PC-PAICE

We surveyed participants and coaches after the conclusion of the first cohort of PC-PAICE including collecting narrative comments to evaluate the experience of our initial PC-PAICE cohort, evaluate the interest of Indian QI team participants in contributing as coaches themselves for a second cohort, and prioritize improvements to the curriculum and methods. The survey used Likert-type responses to assess participants' perceived change in knowledge of QI methods and asked participants to rate the perceived contribution of elements of the course's structure and organization to successful learning. The survey included two open-ended questions that asked respondents to describe the most and least helpful aspects of PC-PAICE.

Twenty (approximately two-thirds) of PC-PAICE participants, representing all the seven teams participating in the project, completed the survey. On average, respondents reported the most knowledge gains in systematic problem analysis and lower knowledge gains in intervention development and sustainability. Exemplary comments included, I have always thought-here is a problem, this is the solution and jumped right into it. PC-PAICE helped approach solutions in a more open-minded approach through various steps and logic. Another participant noted, I had little idea about approaching a problem systematically, I mean identification of the actual problem, finding out the root causes, formulating a key driver approach … PC-PAICE project was an eye opener …

With regard to rating the contribution of specific resources used throughout the collaborative to facilitate learning, the in-person workshop and monthly large group and individual team meetings were regarded as essential by more than half of respondents; whereas, access to Stanford Box resources and RITE videos on YouTube were essential to a minority of respondents. Highly regarded elements of the curriculum reflected modes of didactic instruction and problem solving, whereas, less regarded resources reflected those that required self-directed effort. Notably, current versions of RITE videos that are archived on YouTube use examples that are most applicable to Western learners

Table 3
Participant Ratings of PC-PAICE Elements Essential to Learning

Structure of Collaborative	Essential %
IAPCON 2018 PC-PAICE workshop	61
Monthly PC-PAICE group trainings	56
Team mentor coaching sessions	50
Stanford Box for file sharing	22
Project progress scale review	22
Tools used in collaborative	
A3 template	67
Key driver diagram	67
Run chart	56
Sustain plan	56
Fishbone diagram	50
Graduation template video	28
Pareto chart	17
YouTube RITE videos	11

PC-PAICE = Palliative Care—Promoting Access and Improvement of the Cancer Experience; IAPCON = Indian Palliative Care Conference; RITE = Realizing Improvement through Team Empowerment.

(e.g., solving a QI problem at a bakery) but are culturally less relevant to India (Table 3: Participant ratings of PC-PAICE elements essential to learning).

Lessons Learned From PC-PAICE

PC-PAICE has demonstrated the feasibility of remotely conducting an interventional educational collaborative to support international learning and experience with QI in palliative care. Results suggested that we were also successful in fostering improvement in access to and the quality of palliative care in major Indian cancer and palliative care centers. Our most important goal was fostering organizational capability for improvement, and participants reported a generally positive learning experience with many of the aspects and curricular elements of PC-PAICE. Several Indian team leaders from PC-PAICE cohort have continued to participate as volunteer QI coaches for Cohorts 2 and 3.

PC-PAICE offered important opportunities for bidirectional learning among Indian QI sites and U.S. and Australian coaching sites. Projects focused on topics that hold international relevance, such as promoting earlier palliative referral, more effective allocation of scarce palliative care team resources, and improving documentation and coordination of goals-of-care communication (Table 1). Solutions included modifying workflows and leveraging health care records, changing culture and educating resistant peers, and specific team-created tools and measures.

Similarities among challenges faced by teams in India, the U.S., and Australia suggest that collaborative platforms like PC-PAICE could offer important opportunities for reverse innovation. Also known as trickle up innovation—the principle of reverse innovation emphasizes the potential for innovation arising in less developed contexts to spread to more developed settings.[23] To note one example, many Indian palliative services, particularly in Kerala, use broad networks of community health workers, a promising approach that could inform adoption and use in appropriate contexts in the U.S.[24] COVID-19 highlights the need for such community-based support in the U.S., where older adults with frailty may struggle more than ever to remain independent and at home.

The methods of PC-PAICE were limited by resources available to support it, as well as the nascent status of palliative care and QI in India. PC-PAICE was initially supported by volunteer coaches and donated project and leadership time. A 2018 systematic review evaluated publications of several hundred QI collaboratives conducted during the prior 20 years, highlighting gaps in the methods of collaboratives and the resulting limitations in the evidence for their effectiveness.[25] Because of resource constraints, challenges that limited the rigor of PC-PAICE include each cohort's short duration. PC-PAICE QI projects were also uncontrolled. More rigorous studies of QI will be difficult in India until shared measures are established and routinely collected by palliative care and oncology programs.

At the end of the first cohort, we received a grant from the Conquer Cancer Foundation (Principal Investigator: Dr. Sushma Bhatnagar, All India Institute of Medical Sciences) that allowed us to collect approximately 45 hours of interviews to evaluate the PC-PAICE program in depth and also to evaluate the context for implementing palliative care and performance improvements in India. We interviewed PC-PAICE participants as well as clinical and organizational team members and leaders at the seven geographically diverse sites that participated in Cohort 1.

Establishing an Indian Education and Training Hub

In 2018, the Tata Trusts initiated a QI training and educational hub in Mumbai, in collaboration with the NCG India, with Dr. Nandini Vallath, a palliative care physician, and Dr. Sarbani Ghosh Laskar, an oncologist, in the leadership roles. The vision, reach, and influence of India's NCG, along with recognition of the evidence gap and need to apply QI methodologies widely to India's cancer care centers, strongly favored integration of its QI program with the NCG. A second cohort of seven palliative care sites completed PC-PAICE from this hub in 2018–2019 with training support from the Stanford leadership hub. In 2019, PC-PAICE transitioned into the Enable Quality, Improve Patient care, India (EQuIP-India)

program of the QI Hub-India, and the 2019–2020 cohort was launched directly from the India-based QI hub.

This third cohort broadened its focus and includes projects from both oncology and palliative care. Although the EQuIP-India program remains grounded in the Stanford QI curriculum, with additional, culture-nuanced structure, processes, contents and evaluations, EQuiP-India is rapidly and fully transitioning into a program developing and led from Mumbai, India, and has developed its in-house capacity for mentoring. The QI hub has its own Web page on the NCG main site, and the EQuIP, India program uses the E-learning portal of the NCG to support the projects of participating teams. Each QI project team has a national QI mentor paired with an international mentor to strengthen coaching capacity. The Project ECHO—India platform supports all-hands educational meetings. The third cohort graduated in June 2020.

Change is a constant in health care, and this is particularly true in India where the NCG was established in 2012, and a massive expansion of national health insurance is currently underway. Capacity building in QI is particularly important in this context, contributing knowledge and practical skills in evaluating and acting on the opportunities for change. At the end of June 2020, India had 22 palliative care and cancer teams with leadership capability in improvement methods. With support of the Stanford team, the QI hub itself continues to develop and will assume full leadership of training activities in India including building on the original PC-PAICE curriculum and developing culturally concordant training videos.

The success of this international collaborative highlights the potential for additional shared activity. The expanding network that PC-PAICE established holds potential for robust learning. This could come about through the study of enhanced nuanced implementation, clinical and health services research, and collaborative activity among sites, and oncology and palliative care practices. A future goal is to enhance learning and sustainable QI through the implementation of standard quality measures. Additional details about the PC-PAICE and EQuIP, India cohorts, training, activities, organization, and contact information are available on the Indian NCG Web site at https://tmc.gov.in/ncg/index.php/activities-ncg/q1-india#team and https://tmc.gov.in/ncg/index.php/activities-ncg/q1-india.

In the short term, exigencies like the COVID pandemic raise the bar for means to spread knowledge across organizations and to clinical frontlines. Other interventions like ECHO represent successful and important models for spreading frontline clinical knowledge.[26] PC-PAICE illustrates not only a different aspect but also a critical aspect of diffusion—integrating advances into the organizational fabric of complex delivery systems. EQuIP-India has actually merged the two platforms to foster its goals, and an important area for future research may be the role of combining frontline and organizational strategies in the international context.

Summary

The PC-PAICE collaborative shows that through applying the most practical aspects of improvement methods, coupled with contextual factors that influence change such as mentorship, stakeholder engagement, and empowered teams, learning and improvement can be accomplished in complex environments such as palliative care in India. Teaching and applying proven QI methods is feasible remotely and can be instrumental in addressing difficult clinical and programmatic challenges, even internationally. Teams in India, the U.S., and Australia developed continuing relationships with counterparts that are supporting mutual learning.

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The authors declare no conflicts of interest.

Ethical approval: PC-PAICE was exempted from human subjects review as a QI activity.

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