Special Article

Implementation of HIV Palliative Care: Interprofessional Education to Improve Patient Outcomes in Resource-Constrained Settings, 2004−2012

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Abstract
Palliative care (PC), introduced early in the management of chronic illness, improves patient outcomes. Early integration of a palliative approach for persons with HIV has been documented to be effective in identifying and managing patient-level concerns over the past decade in African settings. The experience of implementing PC in multiple African and other resource-constrained settings (RCSs) emphasizes the need for essential palliative competencies that can be integrated with chronic disease management for patients and their families facing life-limiting illness. This article is an historical description of how basic palliative competencies were observed to be acceptable for health workers providing outpatient HIV care and treatment during eight years of U.S. implementation of "care and support," a term coined to represent PC for persons living with HIV in RCS. The need for team building and interprofessional education is highlighted. The model is currently being tested in one U.S. city and may represent a mechanism for expanding the palliative approach into management of chronic disease. Such competencies may play a role in the development of the patient-centered medical home, a critical component of U.S. health care reform.   J Pain Symptom Manage 2015;50:350−361. © 2015 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

Introduction

Palliative care (PC), described by Saunders in 1977,[1] is optimally integrated with disease management, meeting multidimensional needs of the patient-family unit facing life-limiting or chronic illness. In the U.S., hospice was institutionalized as capitated reimbursement to control rising costs at the end of life (EOL).[2] Since 1990, the World Health Organization (WHO) has promoted integration of pain management and PC, highlighting the relief of suffering and promotion of quality of life regardless of availability of curative interventions.[3] Interprofessional education (IPE) is central to PC and has been refined over the past decade.[4] Simultaneous development of PC and the impact of the HIV epidemic have resulted in application of the palliative approach as an important mechanism for offering support to persons living with HIV (PLWHs) across the trajectory of illness.[5,6]

In resource-rich settings, the implementation of PC has been specialist driven, with recognition that this model will be unlikely to meet the needs of aging populations.[7] Training nonpalliative specialists may be useful in addressing unmet human resource needs in diverse settings. IPE is a palliative skill that has

been applied in chronic disease management. Politi et al.[8] describe three core competencies for IPE relative to patient decision support. These core competencies include 1) ability to identify decision dilemmas; 2) skills in patient-centered communication; and 3) skills in IPE collaboration.[9] Human resource constraints and lack of documentation of cost savings using team care in resource-constrained settings (RCSs) represent barriers to worldwide application of IPE.

In the African setting, recent funding to control HIV has proved successful, and HIV and AIDS are a chronic illnesses for those able to adhere to treatment.[10] Viral suppression, a laboratory marker for disease control, was documented in 86%−90% of randomly selected persons stable for 9−15 months on combination antiretroviral therapy (ART).[11] Despite this achievement, PLWH in African countries suffer from 10 to 26 simultaneous physical and mental symptoms exacerbated by poverty and stigma.[12,13] PC in African settings has been demonstrated to augment patients' outcomes, boost adherence to ART, and improve life expectancy.[14]

This article presents and discusses the evolution of palliative teaching for mixed cadres of health workers implementing HIV care and treatment in U.S.-funded outpatient delivery sites in RCS between 2004 and 2012. Implementation science was the method used to integrate complex medical management into existing health facilities. The original PEPFAR (U.S. *President's Emergency Plan for AIDS Relief*) legislation required that partial funding be directed at "palliative care," with the understanding that not all persons living with HIV disease would have access to treatment and would, therefore, require PC. However, when U.S. federal guidance was developed, the lack of clarity regarding this term in the U.S. in 2004 resulted in a new term called "care and support." From observations in multiple countries, we introduced low-cost palliative strategies for delivering HIV care and treatment.[15] In keeping with the urgent nature of the funding, this was offered as technical assistance and not as a research endeavor. These observations require further study.

In sharing these lessons learned, we intend to "bring them home," considering how they might improve health delivery in the U.S. (Table 1). We propose that simple palliative skills for nonpalliative specialists may be useful in chronic illness, using HIV/AIDS as a model. A study is currently being conducted in one U.S. city to evaluate the impact of a readapted version for nonspecialists applied early in HIV management to improve patient retention in care, having implications for integration of the palliative approach with chronic care delivery in the context of U.S. health reform.[16]

Background: Global HIV Care and Treatment Implementation

Pandemic in RCS

AIDS, clinically described in the U.S. in 1981,[17] had infected 35.3 million people worldwide by 2012. Although annual infections have decreased from 3.1 million in 2001 to about 2.3 million, HIV remains a global pandemic.[18,19] Approximately 16.8 million women and 3.4 million children 15 years old and younger are living with disease. Sub-Saharan Africa remains the most heavily affected area, with an estimated 68% of all cases (22.9 million) and 66% of all deaths occurring in 2010 (19, pp. 20−30). Life expectancy has fallen in countries with the highest prevalence.[20] In 2013, with improved access to ART, mother-to-child transmission in Botswana and South Africa decreased to less than 7%.[21] Now, PLWHs who initiate and adhere to ART early face a normal life expectancy.

U.S. Implementation of HIV Care and Treatment

Before 2004, health delivery in African RCS was predominately episodic and PC, although well described, was applied irregularly outside of South Africa.

Table 1
Lessons Learned from Teaching in RCS

Patient-related:
- Countries share similar problems but cultures vary considerably in the emphasis given and responses
- Patient needs reflect the Saunders approach to "total pain" referred to as the four quadrant approach (P^2S^2)
- Psychosocial and spiritual needs of patients may be overlooked in busy clinics
  - For example, Depression is under-recognized and rarely diagnosed or treated
- Being able to apply knowledge to the individual is what "giving care" is all about
- Small issues get neglected in trying to implement big tasks
- Policies are needed to bring pediatric care in line with adult management

Staff-related:
- Creating a "safe space" for training enables participants to reflect and "grow"
- Hearing experiences from other countries helps us verbalize our own needs
- Cultural beliefs can inhibit learning
- Communication skills are complex and further training is needed
- Decision-making for patients and families needs to be transparent
- True teamwork helps us deal with issues more effectively
- Need for introspection and observation of a process; "not skipping steps" is integral to building something sustainable
- Integrating care for the caregiver energizes and allows us to address our own levels of stress
- Learning to "take a journey" through guided imagery can be useful for any individual in the workplace
- Pooling resources helps everyone

P^2S^2 = physical, psycho-emotional, social, and spiritual.
Adapted from Alexander CS, Memiah P, Henley YB, et al. Palliative care and support for persons with HIV/AIDS in 7 African countries: implementation experience and future priorities. Am J Hosp Palliat Med 2012; 29; 279−285. With permission.

Between 2004 and 2012, the U.S. State Department Office of the Global AIDS Coordinator, through PEP-FAR, first programmed $15 billion to fight the epidemic in 15 focal countries in Africa and the Caribbean. Conceived as an emergency program to provide HIV treatment for at-risk populations, PEPFAR did not originally focus on development of optimal service delivery systems. PC was a core component of the first five-year PEPFAR plan. PEPFAR ultimately provided ART for more than six million people worldwide, with capacity building in 33 countries.[11]

AIDSRelief, a five-member consortium, was one of five implementing partners (IPs), funded to rapidly scale-up delivery of ART in nine African and two Caribbean countries. The overarching goal of this IP was grounded in the scientific understanding that durable viral suppression would be the key to both prevention of spread and management of this mutable virus. Guiding principles focused on the patient-family dyad as a unit of care with four significant arms: 1) improve medical care to identify and treat opportunistic infections as well as the safe and effective use of ART; 2) intensive adherence education and support to achieve viral control; 3) ongoing use of site-specific data to guide improvement of local care and treatment delivery[22]; and 4) effective point of care laboratory infrastructure for evaluation and monitoring of individual patients.[23] This IP worked in Guyana, Haiti, Ethiopia, Kenya, Nigeria, Rwanda, South Africa, Tanzania, Uganda, and Zambia where programs were established in more than 227 not-for-profit and public-based, or missionary hospitals, some of which were established over a century ago. Faith-based clinical facilities constitute nearly half of all African health care. Work of the IP described in this article reached 400,000 individuals enabling more than 200,000 PLWHs to initiate ART.

Transition from PC to "Care and Support"

After early efforts by the WHO to introduce PC in RCS,[24] PEPFAR and private funders such as The Diana, Princess of Wales Memorial Fund[25] enabled renewed momentum in African settings via the African Palliative Care Association and program funding. Despite efforts of the African Palliative Care Association to foster improved EOL care, lack of country-level policy and essential medications resulted in slow progress.[26,27] Before global funding was available, most HIV care efforts in RCS were focused on home-based EOL care. These were the first programs to provide home-based ART with significant adherence support. Between 2006 and 2011, nine African countries offered "isolated provision of services" and four progressed to "preliminary integration" as described by the International Observatory on EOL Care.[28] In Kenya, Uganda, Zambia and South Africa, PEPFAR

funding built on existing PC delivery, and specialist training[29,30] supported application of home-based hospice services for large numbers of PLWHs.

With limited PC funds available, training lagged behind other aspects of PEPFAR implementation as disease management itself was the priority. By 2006, Office of the Global AIDS Coordinator's PC Working Group shifted emphasis from PC by re-labeling this component as "care and support" to include obstacles to implementation of ART. This support included attention to combatting stigma; provision of bed-nets for malaria prevention; nutrition related to comorbid tuberculosis; and only *linkages* with home-based care.

Content: PC Training in RCS

The teaching strategy drew heavily upon Northern training programs.[31–34] Materials from the WHO and individual country programs contributed to the knowledge base.[35] Resources existed before PEPFAR but the evidence-base for integration of PC with chronic illness was being developed simultaneously worldwide. Integration of palliative programming in RCS was described in this journal in 2007.[36] Clinical practices in RCS adhere to WHO guidance aimed at public health priorities, with only selected individual care management. Country-level HIV management guidelines assumed that PLWH would receive the same ART combination. Adding palliative skills, such as communication and behavioral components, represented a complexity yet to be addressed by country guidelines. Without policy, access to PC services and medications remains a challenge.

IP Plan for Introducing PC to Multiple Locations

The opportunity to offer PC training was dependent on country budget considerations. Programs were asked to identify three-to five-member teams to develop expertise in PC. Representatives from six countries attended a two-week introduction to hospice and PC in the U.S. Despite this initial investment, PC received diminishing funding across eight years as health services strengthening was prioritized. In the context of technical assistance delivered by the IP, training focusing on HIV care and treatment including adherence support before initiation of ART, clinical site management, pharmacy coordination, and data monitoring was begun. Within this model, PC sessions were supplemented with home, inpatient, and outpatient visits but all included on-site clinical mentoring. Learners ranged from six to 55 per session receiving core training from an international physician-nurse team supplemented by in-country palliative specialists in social work, pain management, and nursing depending on the location.

The PC training emphasized 1) the recognition of suffering in individual patients with complex medical conditions; 2) teamwork among mixed, rather than segregated, disciplines; and 3) integration of cultural and social aspects of care management. Sessions were iterative, encouraging adult learners to integrate their own knowledge. We introduced the core palliative concept of understanding the trajectory of illness, or prognosis-driven management, to enable learners to prioritize tasks related to clinical management. Emphasis among palliative content domains varied by country health system. Despite lack of guidance for PC, individual IP programs were able to integrate the palliative approach (Table 2).

Table 2
HIV "Care and Support" Activities Implemented in Diverse Settings

Domain of PC	Activities
Epidemiology	• Screening for cancer in targeted populations[a] • Recognition of need for evaluation of individual patient needs For example, pain management; disclosure of HIV status to children • Reasons for death in outpatient HIV clinics[b] from chart reviews ○ High risk for death: 66% Stage 4; Baseline CD4 180 cells/cc³
Pediatric	• Recognize need to address Care and Support needs of orphans and vulnerable children • Need for disclosure of HIV status for children more than seven years of age; Country plan: focused education to achieve this
Symptom management	

Prevalence	Quality improvement audit: demonstrated patients lost-to-follow-up (no. 147)
	Describe population by symptoms for providers to recognize those at high risk: 57% with CD4 <100 cells/cc³ plus cough, fever, chest pain, and difficulty breathing[c]
	• Chart reviews for documentation of symptoms:
	  ○ Challenges clarified: lack of consistent documentation
	  ○ Created audit-guided site education

Pain	• Government introduced oral morphine for pain management • Cosponsored staff training re pain management with local PC organization[d] Pilot project at one clinical site: • Staff interviews: clarified knowledge and attitudes regarding pain • Chart reviews: types of pain in local population: headache most frequent • Barriers identified; resource needs clarified • Poor documentation with regard to pain complaints and follow-up
Mental health[e]	Pilot Project at one clinical site: • Staff interviews: significant number of staff felt overwhelmed • Patient interviews conducted to clarify local language re depression/mood disorders • Staff intervention: to improve morale/overcome burn-out perceived to cause providers to withdraw from attempts to introduce new HIV programming • Barriers identified; resource needs clarified Mental health and clinical parameters are significant factors in determining patients' adherence to their HAART[f]
Communication skills	Use of family meetings[g] • Disclose HIV status to spouse, partner, and family to garner adequate support • Serodiscordant couples—bringing them together, uniting them • Social networking among peers and marriages regarding HIV

End of life	Pilot project at one hospital:
	• Advocacy with staff regarding why EOL issues may be useful to document and discuss
	• Identified need for bereavement training for staff
	• Implemented "memory board" of patients who died to assist staff in "saying goodbye" to individuals.
	• Established a hospital-based EOL team:
	  1) recognized need for documentation of spiritual connections of patients on admission to hospital
	  2) asked community spiritual leaders to visit dying patients and their families
	  3) identified need for "scripting" of these visitors to assure similar messages given distinct tribal and cultural beliefs around discussing EOL
	• Barriers identified; resource needs clarified

Care of health providers	ALL in-country trainings to include attention to care of providers to prevent burnout

PC = palliative care; HAART = highly active antiretroviral therapy; EOL = end of life.
[a]Memiah P, Mbuthia W, Kiiru G, et al. Prevalence and risk factors associated with pre-cancerous cervical cancer lesions among HIV-infected women in resource-limited settings. AIDS Res Treat 2012; 2012:953743.
[b]Bastien B, Dorestan D, Memiah P. B113 Why are they dying? Describing factors associated with mortality among art patients in rural Haiti. JAIDS 2013; abstract B113.
[c]Kaiza A, Shumbusho A, Lekashingo L, et al. CD4 cell counts below 100 as "red flag" indicator of critical need for palliative care services for patients in HIV/AIDS care and treatment clinics in Tanzania. Presented at the African Palliative Care Association, September 2010, Windhoek, Namibia.
[d]Mugisa E, Seruyange H, Ekwaro O, et al. Assessment of palliative care services at ART treatment sites that received training in PC: The AIDSRelief Uganda experience. Presented at the XVIII International AIDS Conference, July 2010, Vienna, Austria.
[e]Effiong A, Alexander CS, Obiefune M, et al. Pilot project at Nigerian antiretroviral (ART) sites to reduce staff stress that may inhibit integration of pain management, end-of-life and mental health issues for PLWHA. Presented at the African Palliative Care Association, September 2010, Windhoek, Namibia.
[f]Memiah P, Shumba C, Etienne-Mesubi M, et al. The effect of depressive symptoms and CD4 count on adherence to highly active antiretroviral therapy in Sub-Saharan Africa. J Int Assoc Provid AIDS Care 2014; 13:346−352.
[g]Oyebola, personal communication.

Impact of Poverty on PC Training

Resources made available through PEPFAR created access to unimaginable options. Patient-centered outcomes were outweighed by institutional factors including shortages of health professionals, hierarchical care delivery, interrupted medication supply systems, and lack of privacy in clinics. The IP approach was to establish simple systems enhancing patient experience through the clinic visit, for example, use of appointment systems and triage by severity. Patient-provider continuity was a significant challenge. Implementation of these modifications promoted team building.

Health workers, having been trained independently, completed tasks in tandem with little formal mechanism for sharing information. Despite having worked in geographical teams, disciplines worked independently without profiting from mixed expertise. Reliance on process documentation in ledgers resulted in little communication about patients. Teams had little opportunity to rehearse working together. Observed obstacles to team building include 1) staffing shortages whereby one person plays multiple roles without allegiance to any department; 2) strict hierarchy exists among disciplines that may interfere with care of the individual; and 3) shear volume of unmentored care delivered daily.

Adaptation of the Curriculum

We gradually refined a modular curriculum for non-palliative specialists using both objective and process from nearly 100 clinical sites in nine countries.[37] Using fundamentals familiar to PC specialists worldwide, we encountered country-specific challenges that made us modify the approach. We also recognized that learning styles in each country reflected educational methods introduced by former colonizers. Each country has multiple tribal beliefs that impact the ability of learners to incorporate new skills. Although in-service education was routinely provided to mixed disciplines, our trainings introduced an iterative component among learners and teachers. As a result, we developed 1) a phased approach to chronic HIV management and a mnemonic specific to PC that could be used with national treatment guidelines; 2) emphasis on self-care for professionals in RCS; and 3) acknowledgment of the impact of poverty on care delivery.

Training goals were not meant to create PC specialists but to improve care for individuals. These include a) respect for racial, ethnic, and cultural aspects; b) recognition of the impact of life transitions upon individuals; and c) acknowledgment of the life-threatening aspects of chronic illness despite therapeutic advances in disease management. Group encounters with patients were facilitated to promote

an interdisciplinary team concept. Self-regulation theory[38] proposes that learners respond consistent with their understanding of the experience and that individuals can be influenced by information.[39] Using this and the four levels of effective adult learning described by Stenhouse,[40] we incorporated the concept that learning activities themselves have intrinsic value in intellectual learning.[40,41] Multidisciplinary home and hospital visits were accomplished to offer simultaneous exposure for learners.

We used a Train-the-Trainer method to implement HIV treatment and named the method the "small test of change" model for ease of use by multiple health disciplines and community workers.[23] This method allows for discussion and behavior rehearsal for adult learners. We were not able to identify adequate indicators to measure PC as process measures are most frequently used. Problem-solving regarding how to integrate new skills with standard clinic operations was integral to IP training[42] (Table 3).

The concept of hospice developed in settings where privacy is standard and achievable. In RCS, both time and space for individual patient care are limited. There is little formal training in behavioral aspects of care management for medical providers and mental health services are rarely integrated. Cultural beliefs among tribes remain explicit and must be recognized

Table 3
Palliative Skills Acceptable to HIV Specialists in One Sub-Saharan African Country

Application of the Palliative Approach for HIV Management in One Sub-Saharan Country

1. Role of prognosis in disease management: Introduction of phases of chronic illness as represented by HIV disease with differing care and support needs by phase
2. Care of care providers: importance of self-care, for example, journaling, singing, prayer
3. Importance of engagement in care based on whole-person assessment: P^2S^2 (Saunders "Total Pain" model)
4. Rank ordering priorities when dealing with patients with complex issues: SCEC (*s*afety; *c*omfort; *e*xpertise; *c*ontinuity)
5. Mental health issues: recognition of continuum of problems faced by HIV patients, use of specific screening questions, and need for referral plans
6. Goal setting by the calendar to avoid crisis-based goal setting
7. Communication skills, for example, ability to discuss difficult topics and to conduct family meetings
8. Pain and symptom management (grading severity of the symptom by asking impact on daily life of the PLWH) from patient's point of view avoiding provider assignment of severity measures
9. Care of the dying: Who dies of HIV? What symptoms do they experience that interfere with interactions with the family?
How to recognize when someone is dying?
Necessary conversations to teach family members
Understanding of local cultural beliefs that impact behaviors near and after the end of life
10. Effects of grief—What are the signs of suffering from grief?

P^2S^2 = physical, psycho-emotional, social, and spiritual; PLWH = person living with HIV.

by care providers before being able to address palliative management. Soliciting and incorporating this knowledge into training was critical. With financial constraints, not all programs could follow-up on concepts raised in these trainings.

Core Content

Medical clinicians in RCS may have had little clinical mentoring and have not developed a specific framework for managing simultaneous problems. We offered a rubric, SCEC (*s*afety; *c*omfort; *e*xpertise; *c*ontinuity), to assist staff to feel confident in offering support regardless of their clinical expertise. We also introduced Saunders's theory of "total pain" to appreciate problems from a patient-centered view.[1] This was represented as P^2S^2, reflecting *p*hysical, *p*sycho-emotional, *s*ocial, and *s*piritual or belief system to describe what we named "the 4—quadrant approach" to understanding PLWH needs.[43] Use of these palliative constructs encouraged a systematic approach to patients. We introduced the five "necessary conversations" used in U.S. hospice programs for families to share near the EOL.[44] The latter precipitated rich discussion as many workers had never discussed their own losses.

To clarify these concepts, we 1) performed chart reviews to clarify what patient-level needs were being documented; 2) described the symptom experience of HIV patients at different phases of illness; 3) discussed comorbid symptom burden such as tuberculosis or malignancy; and 4) introduced simple self-care activities for staff to reduce stress experienced in being required to offer new complex care. After repeated use of similar curricular elements, we identified five fundamental topics that clinical HIV service providers were able to incorporate. These topics include 1) use of a *multidimensional assessment* of the patient/family unit of care to provide the foundation for a patient's plan of care; 2) *communication skills* for discussing topics that are difficult to raise with patients following a *warning statement* to allow for preparation to hear difficult news; 3) use of "calendar-based" rather than "crisis-based" establishment and review of patient/family *goals of care* making these discussions *routine* rather than having critical events drive disease management; 4) documentation and approach to management of specific *symptoms* such as "pain" as they may negatively impact ART adherence and outcomes; and 5), particularly in RCS, recognition of the personal burden experienced by all health disciplines and use of *self-care strategies* to prevent burnout and loss of highly trained professionals (Table 4). Team building was integral to all topics.

Using Prognosis to Guide Clinical Management of HIV

Acute, walk-in care was the common mode of clinical management in most of the settings where we worked with up to 250 walk-ins per day. Patient-centered care—addressing the specific needs of a patient at a particular point in their disease trajectory—was poorly appreciated. To address the prognostic-based approach to care management, we developed a schematic drawing showing a chronological approach to chronic HIV disease where dark spots represent loss of viral control to assist providers in understanding why this approach may be useful (Fig. 1). The model provides clinical staff a mechanism for understanding that patient needs vary at different points in the illness. Thus the emphasis in ART adherence counseling is modified depending on the prognosis of the patient. Referral for EOL care was available through home-based care agencies. When death did occur, we encouraged both staff and families to talk openly about what had happened.

In usual HIV management, all patients are clinically staged to evaluate readiness for treatment. Because context is not often addressed in this process, we

Table 4
Quality Improvement Indicators for Implementation of Palliative Skills

Skill	Mechanism	Indicator
Whole-person assessment and management (P^2S^2 approach)	A. Multidimensional assessment of the patient/family unit forms the foundation for the plan of care (P^2S^2)	Psychosocial and spiritual history documented in medical record: Yes/no
	B. Phase of illness documented quarterly or at each visit	
Communication	A. Use of a warning to alert someone when "difficult topics" are to be introduced	Document that communication took place: Yes/no
	B. Use of family meeting to share difficult to discuss information	
Symptom identification and management	A. List actual symptom	Symptom documented: Yes/no
	B. Quantify impact on patient's daily life	Impact on Life
		Document response to management
Goal setting	Identify goals to be reviewed quarterly or every 6 months per individual site	Documentation of goal with review date
Self-care for health workers	Monthly report of use of self-care by clinicians	Monthly report

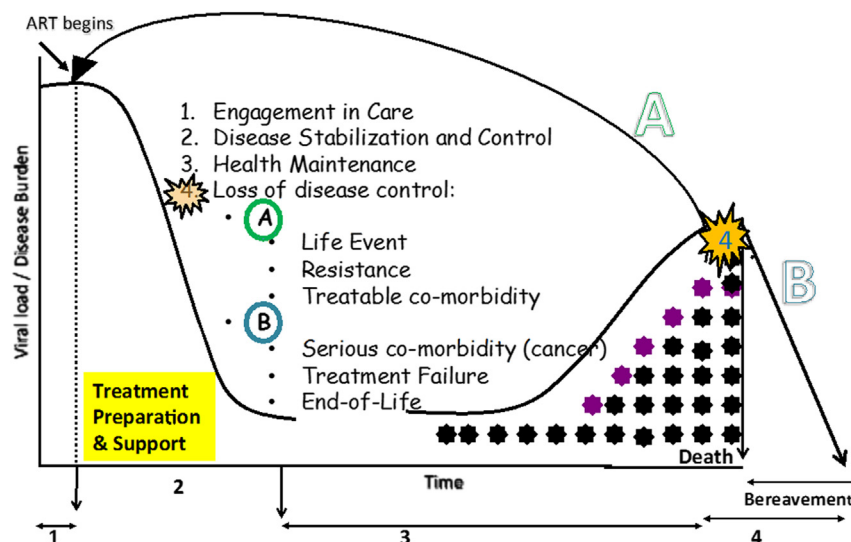P^2S^2 = physical, psycho-emotional, social, and spiritual.

Fig. 1. Phases of care and support for HIV disease. Adapted from Alexander CS. Specific types of illness and sites of care: HIV/AIDS. In: Emanuel L, Librach SL, eds. Palliative care: Core skills and clinical competencies. Philadelphia: Saunders, 2007:372−390. With permission from Elsevier.

offered the phased approach, reflecting underlying HIV biology. These suggested phases of chronic HIV illness are described in the following sections.

Phase 1: Prevention and Engagement in Care. Beginning with the first clinic presentation after HIV diagnosis, it extends until successful initiation of ART. During this phase, the PLWH experiences serious concerns about the future, his/her ability to cope, and sensitivity to stigma. Disclosure of health status is critical to disease management. Inadequate engagement with the clinical team may be a significant factor in early loss to follow-up, resulting in patients not being "in care" until they are symptomatic.

Phase 2: Treatment Initiation and Disease Control. HIV-related infections and sequelae stabilize. Physical aspects of care dominate this phase of adjustment to HIV disease. Counseling and treatment adherence must intensify to achieve desired outcomes. The support system is critical to preventing loss to follow-up.

Phase 3: Health Maintenance. This phase is of indeterminate duration. Concerns reflect resuming a premorbid lifestyle where external issues significantly impact the PLWH. Mental health issues might impair ART adherence, family planning and child-rearing, or "adherence fatigue" itself—all require targeted understanding, attitudes, and skills from providers and staff. Management strategies for this phase are not well described in the literature.

Phase 4: Loss of Disease Control. This phase requires reassessment of current management strategies. A new opportunistic infection, a comorbidity, or loss of viral control all signal a need for changed management. Without a radical response to change, the PLWH can deteriorate rapidly and die without preparation of family or staff. There are three potential routes at this point: 1) this patient may be cycled back for new ART; 2) overwhelming symptoms must be addressed; or 3) appropriate EOL care or referral for community-based care. This juncture requires modified messaging. When death occurs, both staff and families are impacted and acknowledgment of this impact may relieve stress of caregiving.

Team Building Based on Home Visits

In approaching the concept of building teams, we recognized the importance of disciplines sharing their own perspective with one another in an arena where these points of view might be respected. We initiated home visits by mixed cadre teams followed by facilitated discussion to highlight different priorities of disciplines. These visits were eye-opening and resulted in rich discussion regarding potential use of newly identified knowledge. When we introduced "symptom management" as a need of the patient, the newly formed teams reseparated themselves saying that nurses, physicians, and community workers must use different methods for assessing the impact of the symptom on the individual patient. This example highlights the strength of the existing clinical hierarchy to be considered in developing policy when implementing team care.

All disciplines engaged in discussion of the pathophysiology of dying and differences in the impact of grief and bereavement on adults and children. These

discussions elicited long-protected thoughts and feelings from carers about their experiences with patients and their own families. We found that outside of clinic, many staff members had family at home suffering from advanced HIV. With little prior training in management of dying patients, the simple recognition that this person may be near the EOL was a significant learning experience. In many countries, others could not understand why any resources should be available to patients at the EOL when resources are lacking in general.

Importance of Self-Care for Professionals in RCS

Self-care for clinicians is documented as a method for prevention of compassion fatigue in nursing, social work, and medicine. Profound emotional disturbances can occur in clinicians exposed to cancer, chronic illnesses and EOL care[45] and unexamined emotions can lead to provider burnout and depression, thus compromising patient care.[38] To ensure sustainability of changes in practice, priority must be given to self-care strategies; preventing burnout and ensuring continued participation in teams can be addressed through self-care for all disciplines. In RCS, nurses and physicians without prior opportunity to complete supervised postgraduate training have missed the experience of mentored reflection that can assist in making an emotionally traumatic experience meaningful. Without explicit attention to self-care for HIV clinicians, learners are vulnerable to multiple loss syndrome that may resemble burnout, or even post-traumatic stress disorder resulting in possible loss of a trained workforce. Moreover, in RCS, we repeatedly observed that self-care was necessary before other aspects of training could progress.

Self-care for health workers managing patients with HIV/AIDS emerged as a major issue in PC training in RCS. Although mixed discipline professionals excelled at learning technical issues and terms of PC, application was more challenging. Lack of self-care inhibited the integration of principles into practice, compounded by accommodation of hundreds of patients daily per clinic, with limited supplies, cramped clinic conditions, and inadequate water supply, as well as unavailability of medications and inadequate laboratory support. For the individual staff person, waking before daylight to walk miles to a cramped minivan for transport and a repeat of this journey a second time each day, meant that staff were physically drained before addressing the issues of the clinic. Staff members had lost their own family members to HIV yet had little-to-no occasion to discuss this emotional burden. Others, infected themselves, failed to seek treatment because of strong stigma.

Staff members who received direct day-to-day mentoring were more able than others to incorporate new competencies uniformly. Simple, low-cost self-care techniques were integrated into practice. Breathing exercises, being culturally and financially neutral, were easily adopted. Guided meditation was used after careful adjustment to context. Taking an imaginary "vacation," may not have the same significance in an RCS where vacation essentially means time away from work spent catching up on chores at home. Culturally appropriate imagery can be easily identified in conversation with workers. In one large outpatient clinic, this technique was introduced at an all-staff meeting and one week later, about 40% of attendees could describe having positively used this self-care method during the week.[46] Such observations deserve careful study for further evaluation.

Integration of Personal Loss

In one country, didactic training went smoothly but iterative aspects of the session unmasked multiple staff members who had lost family members without ever having discussed these losses with others. Understanding the need for storytelling and meaning-making, we reestablished a "safe space" and facilitated this sharing of meaningful experience. Their incomplete processing of loss had become a hurdle in incorporating new competencies. The training agenda was adjusted to provide a memorial service for the entire group of learners the following day, allowing each person to share an experience with others. The service incorporated seasonal symbols and became a point of departure for incorporation of deeper concepts into practice. Many of these participants were also hospice workers who appeared to feel relieved and became more talkative throughout the remainder of the training.

As a result of these experiences, we built in games and physical activities such as "making a card for someone you love" using colored paper and markers plus seasonal or activity-related stickers. We incorporated spiritual and philosophical readings and discussions to assist learners in appreciating the importance of this type of self-care. After introducing a concept, we formed groups, or teams, to enable learners to act as trainers. Group singing and prayer are commonly used in many countries as a method for group support.

Highlighting Training in Two African Settings

Two countries offered unique circumstances for implementation of the palliative approach with HIV disease management. Although lessons were learned in all countries in which PC training was conducted, the desired experience was incomplete or partial,

reflecting prioritization of other implementation components. More fully elaborated training was accomplished in two countries. This section describes the structure, content, and modes of teaching in those countries. HIV staff had little prior experience in attending to communication skills or in isolating cultural differences in their patients.

Country 1

We were asked to focus, in depth, on three topics for one country where hospice care was only effected in scattered settings. After a one-week introduction to the palliative approach for about 55 mixed discipline learners, program managers requested introduction of pain management, mental health issues, and EOL issues in each of three geographic regions. The management team identified a physician, nurse, and psychologist to be trained as the in-country experts responsible for leading future "Care and Support" implementation efforts. We designed a training framework that could be adapted for desired content per region. Palliative constructs grounded in respect for racial, ethnic, and cultural aspects of the target population and their identified support system[33] became basic to the training for each region.

We used home visits and hospital rounds to introduce multidisciplinary learning groups to simultaneous clinical experience. These teams focused on adapting the "Care and Support" content to their usual implementation strategy. Beginning with advocacy to the target facility regarding intended learning, the team then offered on-site didactic and iterative training with one-on-one mentoring in the clinical setting. Each of these topics raised myriad issues to be addressed locally, including the need for attention to psychoemotional experiences of workers themselves. Content of the pain management training is described in another publication.[47] Table 2 describes "Care and Support" activities implemented in multiple settings.

Country 2

The Minister of Health elected to develop postgraduate HIV specialist training for selected physicians in leadership positions. This country had developed hospice services and simultaneously introduced oral morphine for pain management in hospice settings only. Training was provided as a two-week block on palliative and EOL aspects of HIV care in the context of a one-year postdoctoral program in HIV management and infectious diseases that evolved into a two-year Masters program with required research. Clinical exposure was in a large urban hospital with daily inpatient rounds and outpatient Infectious Diseases Clinic and a second, faith-based care site. Learners were specifically recruited for their potential for future

training in the country and represented experience with all types of health care delivery. Classes ranged from six to 11 participants.

We used a combination of didactic learning and on-site clinical mentoring. The highly iterative nature of the training was case based, using clinical experience of learners and concurrent events to assure uniform exposure to teaching material. Both outpatient and inpatient clinical experience was available for individual learners. Late afternoon on the five weekdays was devoted to combined didactic and experiential learning drawing on the day's clinical experience within the framework of 11 preselected PC topics used throughout the 10 training sessions. Local external events such as illness of a participant or death of a colleague did provide a shared learning experience for these learners. Issues relevant for nonpalliative physician learners were clarified over five separate learning cohorts.

The iterative nature of the development of the training is illustrated in the following examples. During one two-week training session, a medical school colleague of many of the learners died unexpectedly, offering a shared experience of loss for class dialogue. During another training session, a concurrent community hospice training identified significant tribal beliefs and practices related to death operative within the country. This cultural material was incorporated into class discussion where the physicians themselves represented multiple geographical regions. Clinical cases from both inpatient and outpatient settings were incorporated for future learners. We routinely redirected learners' focus to symptomatic needs of patients. For example, young physicians were so distressed by not being able to get a timely oncologic consultation that they failed to notice, in a young woman with lung metastases from Kaposi's sarcoma, that shortness of breath and pain could actually be relieved. While making hospital rounds, we encountered a young man actively dying from pulmonary tuberculosis with his vigilant family at the bedside. This offered the opportunity to model how communication skills were applied when goals of care must change acutely. On another occasion, the clinical team was engulfed with reverberations of wailing just after a death. This was the first time for the providers to discuss the impact on themselves of death of a patient. Each of these exposures triggered extended discussion. One learner disclosed a recent death in his family that allowed the class to talk about their own experiences with mourning and bereavement practices. We were able to conduct an impromptu family meeting as another family, having traveled a distance, arrived to visit a patient nearing death. Having group family discussions is not routine in many African

health settings. Learners were able to see the value and relieved to know that they could follow guidance from the literature in such a situation.

Lessons Learned: Bringing Home Training for Non-PC Specialists

HIV PC training integrating the palliative approach with chronic disease management described in this article addresses unique challenges faced primarily in the African context. A clinical curriculum for specialists caring for PLWH did not exist in the U.S. or Europe at the time the PEPFAR implementation program began in Africa. "Bringing the lessons home" discussed here refers to the implication of the learning in Africa for medical practice in the U.S. and, specifically, the introduction of competencies for nonpalliative specialists in U.S. clinical settings.

Lessons learned in this eight-year experience of training nonpalliative specialists in RCS are summarized in Table 1. Challenges in care delivery are similar across countries despite resources available. Creation of a "safe place" for trainees to reflect and discuss, a need recognized by both trainers and trainees, was a unique experience for most learners. Despite having worked in geographical teams, true "teamwork" was a new concept in most settings and required focused team-building efforts. Cultural issues of both learners and patients are seldom discussed in clinical settings. These cannot be underestimated and pose important issues to be addressed in IPE education. Learners without previous clinical instruction in multidisciplinary assessment and management may need additional steps to prepare for incorporation of palliative competencies into clinical practice. Direct mentorship while evaluating individual patients is critical to the learner's application of new knowledge.[30,48]

The issue of self-care as an essential element of PC training and practice has been emphasized in this article because of the importance it assumed in the training experience described here. Reflection on approaches to self-care in RCS and the U.S. highlights the need to consider this aspect of PC despite an assumption that health workers today have access to support. In the U.S., healthy behavior for clinical staff including regular exercise, diet, and sleep is well recognized yet these efforts may fall short of the immediate stress relief needed in highly structured care delivery sites. The individualistic approach outside the work environment is in clear contrast to self-care developed in the African context, which emphasized group prayer or group singing at the beginning or end of a workday. This group approach to self-care reinforced the cohesiveness of teamwork critical for those working under duress. Group activities such as

recognition of team members and holiday decorations are of equivalent importance in Western hospitals.

Discussion

This report has clear limitations. Teaching tools were developed in the context of a rapid scale up of clinical services under PEPFAR implementation to manage HIV disease. This was not a prospective study to measure effectiveness of the training and outcomes for patients over time. Long-standing literature on efficacy of PC in diverse settings[49–51] and African studies cited previously should be considered as strong support for promoting the tools and methods of PC early in HIV management.

One question raised by this experience in RCS is, can early application of a palliative approach for HIV management be extended to other geographic and cultural settings? A study is currently being conducted in Baltimore, Maryland, to evaluate palliative training for staff for use in early disease management for PLWH known to be difficult to engage in care. The distillation of the African experience presented in this article is being used to refine curriculum we named CASA (Care and Support Access) reflecting the PEPFAR name for PC. Funding for that research conducted by authors of this article comes from the Patient-Centered Outcomes Research Institute, Inc. This funding was created by the Affordable Care Act to improve U.S. quality of care emphasizing the Patient-Centered Medical Home (PCMH), an overarching strategy in U.S. health reform.

Team building is a critical component of current health reform literature. IPE education and multidisciplinary team building should be considered essential for the PCMH to improve outcomes for complex patient populations.[50] Current accreditation procedures for PCMHs may not capture this critical dimension of teamwork needed to improve patient outcomes.[51] Manualized guidelines for creation of the PCMH developed by the Agency for Health Care Quality called "TeamSTEPPS™," may not incorporate interdisciplinary lessons from PC.[52] Care and Support Access describes basic competencies for multidisciplinary practitioners in communicating with individual patients essential for a functional PCMH.

Conclusion

PC has evolved in scope and complexity as it developed in tandem with the HIV pandemic. The experience of implementing PC for PLWH in multiple RCS has provided an opportunity to identify simplified approaches that may be useful for anyone caring for

persons with chronic illness. It cannot be assumed that clinical staff and their patients share cultural knowledge, beliefs, and practices nor that clinical staff are fully aware of these differences. Basic palliative competencies are being studied in the U.S. to improve outcomes for PLWH known to be difficult to engage and retain in care. Findings may be generalizable for improving care delivery for selected chronic conditions being addressed by the PCMH concept.

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References

1. Saunders C. Dying they live: St. Christopher's hospice. In: Feifel H, ed. New meanings of death. New York: McGraw-Hill, 1977:153−179.

2. Berk ML, Monheit AC. The concentration of health care expenditures, revisited. Health Aff (millwood) 2001;20:9−18.

3. Sepúlveda C, Marlin A, Yoshida T, Ullrich A. Palliative care: the World Health Organization's global perspective. J Pain Symptom Manage 2002;24:91−96.

4. Reeves S, Zwarenstein M, Goldman J, et al. Interprofessional education: effects on professional practice and health care outcomes. Cochrane Database Syst Rev 2008;1:CD002213.

5. Alexander CS, Back A, Anderson J, et al. Integrating palliative care into the continuum of HIV care: an agenda for change. In: Workgroup on palliative and end-of-life care in HIV-AIDS: recommendations to the field. Promoting Excellence in End-of-Life Care, The Robert Wood Johnson Foundation, 2004. Available at: http://www.promotingexcellence.org/content/workgroups.html. Accessed April 7, 2014.

6. Simms V, Higginson IJ, Harding R. Integration of palliative care throughout HIV disease. Lancet Infect Dis 2012; 12:571−575.

7. Davies E, Higginson I, eds. Better health for older people. Copenhagen: World Health Organization, 2004. Available at: http://www.palliatief.nl/Portals/31/publicaties/betterpcolderpeople.pdf. Accessed September 2, 2014.

8. Politi MC, Pieterse AH, Truant T, et al. Interprofessional education about patient decision support in specialty care. J Interprof Care 2011;25:416−422.

9. Lown BA, Kryworuchko J, Bieber C, et al. Continuing professional development for interprofessional teams supporting patients in healthcare decision making. J Interprof Care 2011;25:401−408.

10. Office of the Global AIDS Coordinator. Tenth Annual Report to Congress on PEPFAR 2014. Available at: http://www.pepfar.gov/press/c61873.htm. Accessed September 20, 2014.

11. Etienne M, Hossain M, Redfield R, Stafford K, Amoroso A. Indicators of adherence to antiretroviral therapy treatment among HIV/AIDS patients in 5 African countries. J Int Assoc Physicians AIDS Care 2010;9:98−103.

12. Harding R, Simms V, Alexander CS, et al. Can palliative care integrated within HIV outpatient settings improve pain and symptom control in a low-income country? A prospective, longitudinal, controlled intervention evaluation. AIDS Care 2013;25:795−804.

13. Namisango E, Powell R, Atuhaire L, et al. Is symptom burden associated with treatment status and disease stage among adult HIV outpatients in East Africa? J Palliat Med 2014;17:304−312.

14. Harding R, Selman L, Agupio G, et al. Prevalence, burden, and correlates of physical and psychological symptoms among HIV palliative care patients in sub-Saharan africa: an international multicenter study. J Pain Symptom Manage 2012;44:1−9.

15. Alexander CS, Memiah P, Henley YB, et al. Palliative care and support for persons with HIV/AIDS in 7 African countries: implementation experience and future priorities. Am J Hosp Palliat Med 2012;29:279−285.

16. Alexander CS, Raveis VH. CASA: Care and Support Access study for implementation of a palliative approach with HIV treatment. NCT02136680. [protocol]. Available at: http://clinicaltrials.gov/ct2/show/NCT02136680?term=palliative+HIV&rank=5. Accessed October 17, 2014.

17. Gallo RC. A reflection on HIV/AIDS research after 25 years. Retrovirology 2006;3:72.

18. Cohen MS, Hellmann N, Levy JA, DeCock K, Lange J. The spread, treatment, and prevention of HIV-1: evolution of a global pandemic. J Clin Invest 2008;118:1244−1254.

19. Global HIV/AIDS Response 2011. UNAIDS. Available at: http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2011/20111130_ua_report_en.pdf. Accessed September 20, 2014.

20. Kallings LO. The first postmodern pandemic: 25 years of HIV/AIDS. J Intern Med 2008;263:218−243.

21. UNAIDS 2013 Progress Report on the Global Plan. UNAIDS/JC2509/2/E (English original, June 2013) ISBN 978-92-9253-026-6. Geneva, Joint United Nations Programme on HIV/AIDS (UNAIDS). November 2013.

22. Shumba C, Memiah P, Atukunda R, et al. Continuous quality improvement in AIDSRelief supported HIV treatment clinics in Uganda: an evaluation of "See-Try-Observe-Continue" (STOC) model in patient care. Int J Med Public Health 2012;2:26−31.

23. Abimiku AG, Institute of Human Virology, University of Maryland School of Medicine PEPFAR Program (AIDS Care Treatment in Nigeria [ACTION]). Building laboratory infrastructure to support scale-up of HIV/AIDS treatment, care, and prevention: in-country experience. Am J Clin Pathol 2009;131:875−886.

24. Sepulveda C, Habiyambere V, Amandua J, et al. Quality care at the end of life in Africa. Br Med J 2003;327:209−213.

25. Green K, Horne C. Integrating palliative care into HIV services: A practical toolkit for implementers. FHI 360 and The Diana, Princess of Wales Memorial Fund, 2012. Available at: www.fhi360.org. Accessed March 3, 2014.

26. Stjernsward J, Foley KM, Ferris FD. Integrating palliative care into national policies. J Pain Symptom Manage 2007;33:514−520.

27. Harding R, Simms V, Penfold S, et al. Availability of essential drugs for managing HIV-related pain and symptoms within 120 PEPFAR-funded health facilities in East Africa: a cross-sectional survey with onsite verification. Palliat Med 2014;28:293−301.

28. Lynch T, Clark D, Connor SR. Mapping levels of palliative care development: A global update. London: World Palliative Care Alliance, 2011. Available at: www.thewpca.org. Accessed August 5, 2015.

29. Ens CD, Chochinov HM, Gwyther E, et al. Postgraduate palliative care education: evaluation of a South African programme. S Afr Med J 2011;101:42−44.

30. Jagwe J, Merriman A. Uganda: delivering analgesia in rural Africa: opioid availability and nurse prescribing. J Pain Symptom Manage 2007;33:547−551.

31. Emanuel LL, Von Gunten CF, Ferris FD. The education for physicians on end-of-life care (EPEC) curriculum. Princeton: The Robert Wood Johnson Foundation, 1999.

32. Matzo ML, Sherman DW, Penn B, Ferrell BR. The end-of-life nursing education consortium (ELNEC) experience. Nurse Educ 2003;28:266−270.

33. Sullivan AM, Lakoma MD, Block SD. The status of medical education in end-of-life care. J Gen Intern Med 2003;18:685−695.

34. Jacobsen PB, Holland JC, Steensma DP. Caring for the whole patient: the sciences of psychosocial care. J Clin Oncol 2012;30:1151−1153.

35. World Health Organization. Palliative care in cancer. Available at: http://www.who.int/cancer/palliative/links/en/. Accessed April 23, 2014.

36. Callaway M, Ferris FD. Advancing palliative care: the public health perspective. J Pain Symptom Manage 2007;33:483−485.

37. Mckimm J, McLean M. Developing a global health practitioner: time to act? Med Teach 2011;33:626−631.

38. Johnson JE, Fieler VK, Jones LS, Wlasowicz GS, Mitchell ML. Self-regulation theory: Applying theory to your practice. Pittsburgh, PA: Oncology Nursing Press, Inc., 1997.

39. Hochberg MS, Kalet A, Zabar S, et al. Can professionalism be taught? Encouraging evidence. Am J Surg 2010;199:86−93.

40. Stenhouse L. An introduction to curriculum research and development. London: Heinemann Educational Books, 1975.

41. McKimm J, Swanwick T. Web-based faculty development: e-learning for clinical teachers in the London Deanery. Clin Teach 2010;7:58−62.

42. Wagner EH, Glasgow RE, Davis C, et al. Quality improvement in chronic illness care: a collaborative approach. Jt Comm J Qual Improv 2001;27:63−80.

43. Selman L, Simms V, Penfold S, et al. 'My dreams are shuttered down and it hurts lots'—a qualitative study of palliative care needs and their management by HIV outpatient services in Kenya and Uganda. BMC Palliat Care 2013;12:35.

44. Byock I. The four things that matter: A book about living. New York: Free Press, 2004.

45. Shanafelt TD, Balch CM, Bechamps GJ, et al. Burnout and career satisfaction among American surgeons. Ann Surg 2009;250:463−471.

46. Alexander CA, Raveis V, Karus D, et al. CASA study: Care and Support Access—implementation of a palliative approach for HIV+ young men who have sex with men (yMSM) to improve engagement and outcomes. Poster presentation at the 20th International Congress on Palliative Care, Montreal, Quebec, Canada, 2014. Poster PO71.

47. Alexander CS, Pappas G, Obiefune M, et al. Pain management for persons living with HIV disease: experience with IPE education in Nigeria. Am J Hosp Palliat Care 2015;32:555−562.

48. Gwyther L, Rawlinson F. Palliative medicine teaching program at the University of Cape Town: integrating palliative care principles into practice. J Pain Symptom Manage 2007;33:558−562.

49. Temel JS, Greer JA, Muzikansky A, et al. Early palliative care for patients with metastatic non−small-cell lung cancer. N Engl J Med 2010;363:733−742.

50. Wallenstein DJ. Palliative care in the patient-centered medical home. Prim Care 2012;39:627−631.

51. Pappas G, Yujiang J, Seiler N, et al. Perspectives on the role of patient-centered medical homes in HIV care. Am J Public Health 2014;104:e49−352.

52. Agency for Healthcare Research and Policy. TeamSTEPPS®: national implementation. Available at: http://teamstepps.ahrq.gov. Accessed September 18, 2014.