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Palliative care in women's cancer care: Global challenges and advances

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Abstract

Women's cancer rates are increasing in low- and middle-income countries, with presentations that are often far advanced requiring intense symptom management, thus advancing the urgent need to address palliative care. Most resource settings have some options available to assist women with advanced gynecologic cancer, and a combination of leveraging these and expanding on emerging models for palliative care could lessen suffering and improve care for women with gynecologic cancers globally. Providing palliative care for women with cancer is constrained by resources (human and physical), lack of equipment, lack of access, and policy absence or barriers. There is important work to be done in advocating for appropriate infrastructure development and legislation to assure that these options are available to women and their families. Access to adequate opioid and other pain relief options for cancer-related pain is a particular concern given that availability, cost, and legislative prohibitions create barriers that cause suffering for patients and grief for their families who are unable to address their suffering. All of these require ongoing advocacy for continual advances to improve access and infrastructure for palliative care.

KEYWORDS

FIGO Cancer Report; Global palliative care; Gynecologic oncology; Women's cancers

1 | INTRODUCTION

The concept of integration of palliative care into the entire spectrum of cancer care, from diagnosis through survivorship and end-of-life needs, has expanded our understanding that supportive care is needed at every point in a patient's cancer journey. The term palliative care has been so highly linked to end-of-life care and life-limiting diagnoses that the benefits of a sustained focus on maximum supportive care for symptom relief throughout cancer treatment has received less attention.

Cure and maximum supportive care can and should be considered concurrently with leveraging cancer therapies that treat the disease to assist in alleviating pain and suffering when cure is not an option.

Palliative/supportive care across medical, psychosocial, and spiritual domains of comfort and healing must start right from the time of diagnosis. The needs and approaches to those needs shift continually over the cancer journey, whether life limiting or not, as cancer and its treatment leave a legacy of needs even for those who survive the disease process itself.¹ This is supported by patient, family, and caregiver education to create an understanding of the disease process and related symptoms over time. If this education is neglected, it results in what might have been avoidable fear and suffering for both patients and their families when they interpret normal adverse effects or terminal progression of disease as emergencies, causing great anxiety and disruption, rather than having the education and planning for relief of expected pain or symptoms.

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Cancer and other noncommunicable diseases have higher rates in low-and middle-income countries (LMICs), with presentations that are often far advanced requiring more focused and intense symptom management, as well as an increasing incidence in all settings; this supports the urgent need to address palliative care for women with cancer. Most resource settings have potential options available to assist women with advanced gynecologic cancer and their families. Utilizing these options and expanding on emerging models for palliative care can lessen suffering and improve care for women with gynecologic cancers of all stages globally. Not only does early integration of palliative care improve quality of life, lessen depressive symptoms, increase symptom control, and decrease introduction of aggressive treatment that offers no benefit at end of life, early integration of palliative care may have the paradoxical effect of lengthening survival. The early implementation of this strategy in non-small-cell lung cancer patients, for example, remarkably improved quality of life, mood, and slightly lengthened survival.²

Key questions about palliative care include: What are the barriers or challenges to palliative care in low- to medium-resource settings? How could care be organized? What are the effects of changing patterns in management of symptoms and timing of interventions? What are the social, policy, and economic challenges to effective palliative care?

Answering these questions for gynecologic oncology depends on assessment of the individual needs of each patient across all domains of care and providing support for their decision making, identification of the goals of treatment, and assuring care is coordinated locally as well as at specialized centers at each point in treatment. Clearly more research to expand options and refine use during the entire care cycle is of importance to patients and their families.

2 | PALLIATIVE CARE IN LOW-RESOURCE SETTINGS: CHALLENGES AND BARRIERS

In August 2017 the Uganda Cancer Institute (UCI) and the Palliative Care Association of Uganda (PCAU) hosted an international conference in Kampala, Uganda. The key message from the conference was that cancer care should include prevention, early diagnosis and screening, treatment, rehabilitation, and palliative care in line with the recommendations of the WHO for national cancer control programs. A major concern regarding patients with cancer in countries such as Uganda is that up to 80% of patients will present with advanced-stage disease. Uganda is one of the leading countries in Sub-Saharan Africa providing palliative care. A recent publication indicated that 216 hospitals in Sub-Saharan Africa were providing hospital-based palliative care services and there were 13 stand-alone hospices along with home-based care services, enabling integration of palliative care into some healthcare services.³ The conference recognized the importance of universal health coverage in the provision of palliative care, as well as the May 2017 World Health Assembly endorsement of cancer control and prevention.⁴

It was also acknowledged that while LMICs share the biggest proportion of cancer burden, with one-third of global cancer care needed in Sub-Saharan Africa, the lack of access to appropriate

technology, health systems, services, radiology, pathology, and anti-cancer therapies results in poor outcomes and survival in those diagnosed with cancer.

The availability of palliative care support varies widely throughout the global health network. For example, an atlas of palliative care options in Latin America recognized wide variations by country, with the largest concentration of support in Costa Rica, but a wide gap between the 16.06 palliative care services/units/teams per 1 million inhabitants in Costa Rica and the corresponding figure of 0.24 in Honduras at that point in 2012.⁵ An important part of this analysis was identification of the parallel variation in training in palliative care both in number of personnel accredited (highest in Mexico, Argentina, and Chile) and inclusion in the medical school curriculum, with some countries without any teachers or curriculum in the medical school. The initiation of formal palliative care clinics was credited to Dr Tiberio Alvarez in Medellin, Columbia, in the early 1980s; however, development has been erratic and sporadic across the region since that time, although all countries now have some level of palliative care support. Disparities in access to adequate pain management, symptom management, and advanced planning and education continue throughout the region.⁶

A major issue in LMICs for cancer care and palliation is access to essential medicines, including medicines such as oral morphine. Uganda has initiated a successful program of training nurses to administer oral morphine and shown that nurses can manage pain with insight and expertise.³ Other needs for cancer care and palliation are lack of resources for cancer care, expressly financial, human resources, and lack of equipment for radiotherapy, chemotherapy, surgical oncology, and laboratory backup to enable administration of various anti-cancer therapies.⁷

3 | ORGANIZING AND INTEGRATING PALLIATIVE/SUPPORTIVE CARE

3.1 | Who? When? Where?

Depending on the resource setting, the front line for palliative/supportive care may be family and community or it may be in a medical setting. Access to palliative care is poorly developed in the global cancer care community, and care falls to poorly prepared family members or healthcare professionals who have little exposure to the types of complications these patients have, let alone options for symptom and pain management. Having a form of home-based support service can substantially improve palliative care services. If knowledge is expanded to primary care and community-care-based health workers, better support for home-based care and control of symptoms can be achieved.⁸ Furthermore, costs of care substantially diminish.⁹ However, migration with loss of extended family support in more rural areas, shifting cultural understandings of locations and contexts of care, as well as differences in drug availability across countries and regions provide arguments for multiple layers to address the needs of women with cancer, particularly for pain management.¹⁰⁻¹² Kimani et al.¹¹ argue that a "multisectorial collaborative approach in

which palliative care is viewed as a responsibility for all and not just a select few is needed." Given the overall lack of palliative care specialists globally, the responsibility for delivering quality palliative care devolves to oncologists, primary care, and health workers to educate, advocate, and support care for women with cancer in their practices and communities.

3.2 | The central role of communication

Much has been made about cultural differences in conceptualizing cancer as well as end-of-life care. Yet careful review reveals more commonalities than expected.¹³ Bias on the basis of age can also lead to failure to offer options, such as the use of palliative chemotherapy even though the adverse effects versus benefits may be acceptable and even desired by an elderly woman with cancer.¹⁴ For cancer care in general, avoiding pain and alleviating major symptom groups, such as gastrointestinal distress and neuropathic symptoms, is virtually universal. The meaning attached to where that care is given and where someone might die may be culturally and generationally nuanced, but even within cultures and age groups it varies by individual and context.¹⁵ Given this observation, the ethical obligation to respect the patient as the owner of decisions regarding what care is acceptable and where, is even more critical. This requires a level of gentle truth telling that allows a patient and her family to understand the status of the disease, so that there is trust built over time that the caregivers will both tell the truth and also accompany the individual on the journey, or find someone to do so.

Assuring authenticity and autonomy for decision making by each woman among the options available to her, regardless of cultural context, is a responsibility of the health profession. First and foremost, this requires early and ongoing discussion with the patient about how she would like to receive information. This may require accepting that, for some, decision making by someone else or by consensus of family members is preferable, and assuring that those decisions made represent her desires for level of care and understanding of the outcomes of those options for her. Surrogate decision makers, however, often struggle with being given responsibility for decisions that they see as making a choice for their family member, particularly when it involves not offering more aggressive care and making death seem more imminent.¹⁶ Making observations to provide guidance to family members or patients is often important, and is needed to move forward without engendering guilt. For example, sharing decision making with a comment such as "I have noticed that many of our patients choose X, and observe that we are able to provide a higher level of comfort with that approach" provides additional information that the family and patient can use without assuming that this patient would choose similarly. Finally, an axiom of cancer care, even for end-of-life care, is the acknowledgement that hope endures even when illogical from a medical viewpoint, and may benefit patients even as they acknowledge the likely fatal nature of their disease.¹⁷ In fact, the creation and continuation of hope may serve to provide resilience and improve quality of life and symptom management for a patient and does not need to be seen as something to be eradicated

or to be made more "realistic." There are also patients who simply want to deny any chance that death may occur from complications, adverse effects, or the disease itself. If the opportunity to discuss and consider the information has been given in the patient's context, it is neither required nor desirable to disabuse a patient of a sense of hope as it will likely fail and furthermore serve to decrease rather than increase communication.

4 | CHANGING PATTERNS IN MANAGEMENT OF SYMPTOMS AND TIMING OF INTERVENTIONS

There is a growing body of literature about options and advances for managing the myriad symptoms that cancer therapy and end-of-life supportive care present, including comprehensive reviews and guidelines.^{18,19} The most important advance is consideration of treatments as prevention and in continuity with the care no matter where a woman is in the cancer care journey. Two notable examples of this philosophy are the management of pain and the management of constipation and gastrointestinal adverse effects.

Early integration of preventive measures for constipation and bowel regulation is an initial palliative care concept that is so fundamental that it should be routinely integrated at the beginning of therapy. Diet, senna, and polyethylene glycol to assure continued bowel motility with constipation induced by chemotherapy or pain medication should start concurrently with that therapy. Stent use for various levels of obstruction of the gastric outlet or a defined area of the bowel has continued to expand options for management of obstruction,²⁰ although diversion if surgically feasible remains that mainstay. One Australian study suggests that if stenting is feasible, it may offer significantly reduced procedure time, reduced hospital stay, and earlier return to diet for large bowel obstruction.²¹ For localized pelvic progression (cervical cancer more commonly), these stenting options may offer new approaches. Malignant obstruction related to advancing ovarian cancer, which often results from multiple sites being affected, presents a particular problem because evaluating the potential for benefit from surgery is more complex with multiple sites and the likelihood that a single stent can alleviate the problem is less.²² In this circumstance, agents to reduce bowel motility may counterintuitively be of value, as well as direct gastrostomies or enterostomies to provide venting ahead of obstruction. The use of diversion of flow with gastric suction (nasogastric or gastrostomy) and reduction of bowel motility is also a goal with enterocutaneous fistulae, and the use of somatostatin, if available, can assist. Cutaneous fistulae present a particularly difficult problem for palliative care, for which careful skin protection through frequent zinc oxide application, use of powders, ostomy devices, as well as suction devices may all be of assistance; however, there are few advances in palliative management on this front. As noted throughout this article, tailoring to each patient's individual needs is the most critical component of identifying options for palliation of symptoms.

4.1 | Pulmonary symptoms

One developing area in the management of pulmonary complications, including malignant pleural effusions, is the use of hyperthermic pleural/intrathoracic chemotherapy, following the model used successfully for intraperitoneal management of malignant ascites. A systematic review showed some evidence that this improves symptoms but may influence length of survival in those treated, including breast and ovarian cancer patients.²³ There is additional research into pressurized intrathoracic sprays of chemotherapy, which also shows promise. This option is targeted more toward early palliation when starting initial or second-line therapy and not when managing terminal pulmonary issues. Finally, use of medical grade talc or bleomycin as a sclerosing agent continues to be an option for all stages of management. Long-term and terminal management rely on the beneficial effects of morphine for air hunger and pulmonary taps, as needed, for comfort.

4.2 | Bone metastases

Radiation for management of painful bone metastases remains a mainstay of palliative care; however, other approaches may offer alternatives. For example, magnetic resonance-guided focused ultrasound hyperthermia as a local therapy is one approach gaining ground that may provide options for a wider band of resource settings, particularly if the focus can be provided by means other than magnetic resonance imaging.²⁴ In addition, targeted embolization and chemotherapy may have a role and could be explored in appropriate candidate patients.²⁵

4.3 | Agitation management

Delirium and agitation can be some of the most distressing symptoms for patients and their families, and treatment is not straightforward. Given the complexity of diagnosis of the root causes, and therefore appropriate therapy, the use of a protocol or algorithm to guide therapy has great benefit. These protocols, such as one used in Portugal, often use haloperidol and escalate with midazolam if not controlled with generally good effect.²⁶ The use of environmental cues may be of benefit, with music, lighting, tactile stimulation from covering or gentle massage, and aromatherapy all offering additional reduction of agitation and increased relaxation.

5 | SHOULD RADIATION AND CHEMOTHERAPY BE CONSIDERED FOR PALLIATIVE TREATMENT WHEN UNLIKELY TO EXTEND SURVIVAL?

Any therapy offered must meet a goal of medicine, such as alleviating suffering and providing pain relief. Ethically, the therapies offered need to be weighed against their potential harm (therapeutic proportionality), but often targeted radiation or limited chemotherapy can

accomplish that goal. However, it is clear that aggressive chemotherapy with limited benefit is still offered with diminished quality of life, particularly for elderly patients.²⁷ This is not meant as a prohibition of chemotherapy or radiation, as there are limited trials and areas where this still offers help; for example, there is potential benefit for chemotherapy in intractable malignant ascites, where such treatments as hyperthermic intraperitoneal chemotherapy or other innovations may ultimately be shown to offer relief.²⁸ However, the lack of value from simply continuing treatment because the patient “wants” to continue it and cannot consider not “treating the cancer,” along with the adverse effects on quality of life and the overall costs, need to be honestly addressed with patients. Moving patients and families from “active cancer treatment” to “active symptom management” is a critical skill and an obligation of caregivers to respect our responsibility to benefit our patients and not cause harm, even if they “want” treatment.

6 | WHAT ARE THE SOCIAL, POLICY, AND ECONOMIC CHALLENGES OF EFFECTIVE PALLIATIVE CARE?

6.1 | Palliative care must be prioritized as the responsibility of cancer caregivers

Palliative care is a critical component of cancer care, regardless of the resource setting. However, availability of resources, education of providers, and lack of communication skills work together to add to the suffering of patients and their families. With this in mind, programs that research locally relevant interventions and protocols are critically needed. A good example of a positive step forward is work undertaken in Ghana to institute a structured approach to end-of-life decision making with the purpose of improving the quality of care that patients receive.²⁹ The key elements of this intervention included sensitizing providers to find openings (triggers) to discuss end of life; listening to the needs and concerns of the patient and family; clarifying the goals of care, which may change over time; and making sure there is agreement on the next steps in treatment. While the group was small in this study, there was a clear advantage to following a “protocol” to advance communication.

Sensitivity surrounding who needs to be included in this discussion is critical for success. For example, many cultures consider this to be an extended family discussion and not just an individual patient discussion, and inclusion of all members of the family makes a significant difference to the success of palliative interventions.³⁰ This is a lesson that is relevant across all resource settings. Listening to the needs of patients and their families, giving them openings (and then taking them) for discussion of end-of-life issues, and agreement on the interventions and treatments while weighing the benefits and harms, are some of the most basic skills of medicine—and critical to palliative care in all settings.

Additional advocacy and education are needed to advance legislative attention for infrastructure needs, from education of health providers to availability of hospital- and home-based supportive

services. Furthermore, assuring that patients can address their wishes for end-of-life care with advance planning and directives without additional barriers (such as requiring a notary, which may not be available locally) needs to be an area of active policy and legislative activity in countries where this has not been covered.⁶ Access to adequate opioid and other pain relief options for cancer-related pain is a particular concern given that availability, cost, and legislative prohibitions create barriers that cause patients to suffer and grief for their families who are unable to address their suffering.³¹ All of these require ongoing advocacy for continual advances to improve access and infrastructure for palliative care.

7 | SUMMARY

Palliative care is a critical part of all cancer care whether the focus is on curative care, maintenance, or end-of-life care. Providing options for women with cancer is constrained in various settings by resources, but the need to continuously address the best symptom management during and after cancer care remains a major responsibility of cancer care providers (Table 1). Medical advances are bringing new options in some settings, but the engagement of the patient's community and family and the need for continuous, honest, and supportive communication are the keystones of providing palliative care. There is important work to be done in advocating for

TABLE 1 Areas for advancing palliative care: one or more may be the critical focus for advocacy by region or country.

Infrastructure to advance successful palliative care programs	Common barriers to be addressed: examples
Adequate human resources/training	Lack of healthcare workers in specific areas (rural), lack of educators/trained professionals in palliative care, lack of mandate for palliative care training in nursing/medical/health professional education, lack of cancer care providers overall
Equipment/services	Lack of access to radiation therapy, chemotherapy, appropriate operating rooms, equipment for management of stoma/fistulas, delivery systems for narcotic/opioid pain relief; lack of respite or hospital-based palliative care; lack of adequate home-care support
Policies and monitoring	Lack of country-wide information on women's cancer care including access to palliative care; lack of legislation to support advanced end-of-life planning; policies that inhibit adequate pain control access particularly at end of life
Public awareness and education	Lack of knowledge about healthcare rights; lack of knowledge about course of disease and options for support/care; lack of community knowledge about palliative care

appropriate infrastructure development and legislative and policy supports to assure that there are palliative care options available to women with cancer globally.³²

AUTHOR CONTRIBUTIONS

Both authors were actively involved in all aspects of manuscript preparation including writing and editing.

CONFLICTS OF INTEREST

The authors have no conflicts of interest to declare.

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