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REVIEW ARTICLE

Current state of palliative and end-of-life care in home versus inpatient facilities and urban versus rural settings in Africa

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ABSTRACT

Objective: Because palliative care in sub-Saharan Africa may not fit the style of delivery of palliative care in the global north, exploring the evidence can serve to reduce existing barriers and help streamline national policies that determine the optimal setting to implement formal palliative and end-of-life services.

Method: A search was conducted in Ovid MEDLINE®, PubMed, and Google Scholar databases using the search terms nursing care, terminal care, end of life care, palliative care, dying, death, hospice, opioids, morphine, Africa, sub-Saharan Africa, caregivers, and place of death. Eighty-seven relevant articles were found using the search terms. Of these, 22 matched inclusion criteria and were reviewed.

Results: Opioid availability and distribution is best accessed at the inpatient level, and hence, pain and end-of-life symptoms are best managed at the inpatient level. Despite the great need, nurses' lack of prescription power in the home-based setting is a shortcoming. Home deaths have not been adequately studied, but research suggests that palliative care generally causes economic strain, psychosocial distress on family members, and increased risk of transmission of communicable disease. Hospice is understudied but shows favorable outcomes.

Significance of results: Funding and research need to focus on development of inpatient palliative and hospice care units in urban areas. In rural areas, the priority should be a home-based care model that involves nurses who are privileged to prescribe opioids and adjunctive medication therapies.

KEYWORDS: palliative care, end-of-life care, Africa, home, urban, rural

INTRODUCTION

In Africa, the needs for palliative care are not met by the available resources. Each year in Botswana, Ethiopia, Tanzania, Uganda, and Zimbabwe ~ 610,000 people die from HIV/AIDS and 80,800 die from cancer in a population that totals 135,000,000 (Sepulveda et al., 2003). The World Health Organization (World Health Organization, 2004) estimates that at least 1 in every 200 individuals each year in Africa needs palliative care. Because of the prevalence of cancers and Africa's HIV/AIDS epidemic, WHO projects that at least 50% of patients with HIV and 80% of patients with cancer will experience severe pain during the terminal phase of their disease (World Health Organization, 2004).

The need for palliative care is evident, yet the resources are scarce. There is a paucity of information on palliative and hospice care provision in Africa and a weak evidence base upon which to build policy

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and practical development (Clark et al., 2007). Studies have revealed that palliative care has different characteristics in different regions varying from community home-based healthcare to hospital-focused care. In addition, the vast majority of hospice care in Africa consists of nongovernmental and faith-based organizations that operate on inconsistent models of care.

Many studies also emphasize the importance of the home as part of the African identity. As individuals and families migrate, they tend to identify with their birthplace to which they long to return (Kruger, 1998). Based on this, healthcare has shifted strongly toward a home-based focus. A systematic review of the literature by Lerberghe et al. (1997) found that the declining African economy in the 1990s resulted in failure of hospitals to continue operating. When governments failed adequately to fund both small and larger hospitals, donor agencies, nongovernmental organizations (NGOs), and grassroots foundations began to take over many of the healthcare programs (Lerberghe et al., 1997). However, a consensus for operating healthcare programs was reached through a vague understanding of healthcare implementation and access. During a time when disease control programs and hospitals were facing discredit, healthcare developed a home-based focus under the assumption that the majority of Africans maintain a rural lifestyle. Whereas historically this may have been true, economic evolution and migratory shifts demonstrate a deviation from this pattern.

The future success of African palliative care requires engagement with institutionalized healthcare systems as well as guidelines on policies and strategies for development (Clark et al., 2007). In order to achieve this, policy makers must agree on optimal settings for palliative care. The purpose of this article is to examine opioid availability, caregiver burden, and the use of healthcare resources at the end of life by setting in order to determine the optimal setting for palliation at the end of life. The settings evaluated in this article include community home-based care programs, hospital institutions, and acute care hospices. Palliative care in Africa may not fit into the mold of the global north; however, given the present situation, exploring the evidence can serve to reduce existing barriers and help streamline national policies that determine the optimal setting in which to implement formal palliative and end-of-life services.

METHOD

A search was conducted in Ovid MEDLINE®, PubMed, and Google Scholar databases using the search terms nursing care, terminal care, end of life care, palliative care, dying, death, hospice, opioids, morphine, Africa, sub-Saharan Africa, caregivers, and place of death.

We eliminated studies that did not address populations in Africa or patients at the terminal stages of illness. We also eliminated studies that assessed death from trauma, studies on children with acute symptoms of HIV/AIDS not facing the end of life, and feature stories without specific information pertaining to data or studies. We also excluded studies that were not available to read in full. We did not exclude studies based on year of publication. We included multi-method reviews involving synthesis of published evidence, cross-sectional data survey, retrospective review of records, and qualitative data based on interviews and questionnaires. In addition, we included editorials that contained relevant information on palliative care, articles published by volunteer organizations such as Red Cross, and online organizations such as the African Palliative Care Association and WHO. Of the articles that were found to qualify for this review, the references sections were searched for any additional studies that fit the criteria.

RESULTS

A search of the databases yielded 87 relevant articles found using the search terms. Of these, 22 matched the criteria. Sixteen were qualitative studies that included interviews, surveys, questionnaire, or multimethod reviews that involved a combination of the three. Four articles were statistical analyses of medical records. The articles also included one feature story and one cost accounting analysis designed to measure unit costs. A search of the references sections of each article yielded no additional articles that were available for inclusion, because of lack of article access.

Of the 22 articles deemed eligible for inclusion, eight directly addressed opioid availability, distribution, and usage in palliative care (Table 1). The studies looked at funding for opioids, described the distribution by country and setting, and evaluated usage of opioids according to type of setting.

Table 2 gives a description of caregivers as found in eight articles. Of the eight articles, five evaluated health professional caregivers (for example, nurses, volunteers, and hospital workers), and five looked at family caregivers. Table 3 looks at the ability of both professional and family caregivers to recognize and treat signs and symptoms at the end of life. Eleven studies are included in this table.

Finally, nine studies looked at use of healthcare resources. Table 4 shows studies on place of death, issues with patients being admitted to the hospital at end of life, and availability and use of hospice.

Table 1. *Studies comparing opioid analgesic availability in sub-Saharan Africa*

					Finding about opioid availability	
Reference	Region	Methods	Participant characteristics	Distribution	In hospitals	In home settings
Beck (1998)	South Africa	Ethnographic design: semi-structured interview. Completion of inventory of System Barriers to Opioid Availability tool.	Total sample = 33 Physicians = 10 Nurses = 12 Pharmacists = 4 Social workers = 3 Pastoral care = 2 Physical therapist = 1 Business = 1	Governmental agencies, NGOs, private and public healthcare facilities, rural and urban, inpatient, outpatient, and community based.	Poor individualization of pain control. Incorrect dosing. Unnecessary drug interactions. Ineffective dose scheduling (sustained morphine often mis-scheduled).	Nurses unable to distribute morphine (except midwives).
Beck and Falkson (2001)	South Africa	1st Phase – screened for prevalence of cancer pain in various settings 2nd phase – screened for pain details and management. Questionnaire included complete set of items from brief pain inventory from the Pain Research Group, Department of Neurology, University of Wisconsin-Madison.	Adults ≥18 years of age with diagnosis of cancer. 1st phase = 263 94 of 263 experienced pain 2nd phase = 426	Site 1: 340-bed hospital in urban Pretoria Site 2: 1000-bed teaching hospital in Capetown.	30% patients overall not receiving adequate analgesic levels. Non-opioids were used most. Almost 30% patients also taking sedative/hypnotics, laxatives, steroids, topical anesthetics, anti-emetics. Inpatient setting had highest reported level of pain. Hospice patients had lowest level of “worst pain.”	Not evaluated

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Table 1. *Continued*

					Finding about opioid availability	
Reference	Region	Methods	Participant characteristics	Distribution	In hospitals	In home settings
Clark et al. (2007)	Participating African countries	Multi-method review involving synthesis of evidence from published and gray literature, ethnographic field studies, qualitative interviews, and collation of public health data.	African country reports = 26 Interviews total = 127 Participants = 97 African countries = 14	Ministry of Health- Kenya Districts – Uganda NGOs, Hospice Uganda (HAU) The Hospital Association of Zimbabwe- Zimbabwe Hospice and palliative care association of South Africa- South Africa	Kenya – No official palliative care policy. Ministry of Health supplies morphine to Nairobi Hospital. Uganda –integrated palliative care in health systems at district level (HAU, NGO efforts). Zimbabwe- 13 NGO organizations. Island Hospice NGO strong advocate. The Hospital Association of Zimbabwe (HOSPAZ) public voluntary organization, strong advocate. South Africa –Hospice and palliative care association of South Africa (HPCA) links 60 organizations together. Small amount of money from government- but hospice must supply most of its own funds.	Uganda provides morphine in the homes where nurses can prescribe and distribute.
Logie and Harding (2005)	Uganda	2005 Multi-method protocol appraised morphine regulation, storage, prescribing, and consumption via voluntary interviews.	Phase 1: Interviews Clinicians prescribing morphine = 16 Patients accessing morphine = 10 Key informants (governmental staff) = 16 Phase 2: Direct observation of morphine distribution Phase 3: Quality of clinical care audit. Nurses prescribing morphine at home = 21 Clinical note standards = 50	Governmental district hospitals = 2 Rural home based NGO programs = 2	Hospital staff shortages hindered opioid availability: tertiary referral hospital in Kampala only had 1 palliative care trained nurse qualified to administer morphine. Shortage of pharmacists (only 200 in Uganda) was barrier. Pharmacies were inadequate to hold 500 mL bottles of morphine. Larger cupboards were too expensive for many pharmacies. Drug bookkeeping was too complicated for many inspectors to complete.	Patients could not afford repeat travel to clinic/ hospital. Many moved to be closer to site of free morphine.

Bates et al. (2008)	Malawi	Qualitative study to investigate beliefs, attitudes, practices of clinicians, nurses, and staff in Southern Malawi.	Interviews = 15 Hospitals sites = 5	Global Fund – humanitarian initiative	Between 1990 and 2007 INCB received only one annual report on morphine use from Malawi. Morphine (slow release 10 mg tablets) supplied free of charge to all Malawi hospitals that deliver anti-retroviral drugs as part of care package supplied by Global Fund since 2004. National morphine stock has been empty since 2006 because of lack of adequate routine reporting. Morphine could not be imported in 2007- national quota reached.	Not evaluated
Alsirafy (2010) Opioid needs of patients with advanced cancer and the morphine dose-limiting law in Egypt *Journal of Palliative Medicine*	Egypt	Retrospective review of medical records of advanced cancer patients referred to the Palliative Care Medicine Unit (PCMU) or NEMROCK during its first several months from September 2008 to March 2009.	117 out of 141 cancer patients referred to PMCU with advanced cancer. Each prescribed limit of 420 mg oral morphine per weekly visit.	PMCU of Kasr Al-Aini Center of Clinical Oncology and Nuclear Medicine	Dose limitation of 420 mg oral morphine per week by the Egyptian Narcotics Control Law does not provide adequate morphine doses for pain control. 50% of total patients required strong opioid; 26% of patients requiring strong opioid needed doses adequately covered within 420 mg weekly limit. Mean dose required by total patients = 132 mg oral morphine equivalent (OME) per 24 hours. Mean dose required by patients with confirmed death = 121 mg OME per 24 hours. No parenteral morphine.	Not evaluated
Harding et al. (2010)	Participating African countries	Cross-sectional survey integrating data from palliative care facilities in 12 African countries		62 palliative care facilities defined as tertiary specialist facilities (hospice) South Africa = 27 Uganda = 8 Zambia = 8 Kenya = 6 Tanzania = 4 Nigeria = 3 Botswana = 1 Cote d'Ivoire = 1 Ethiopia = 1 Mozambique = 1 Namibia = 1 Rwanda = 1	South Africa had most care facilities with documented distribution of opioids. 35% of surveyed sites were tertiary care facilities including hospice. 8.1% of surveyed sites were primary or secondary level, such as hospitals or clinics. Ethiopian Competent Authority reported opioid availability but no opioids were found in care facilities surveyed.	56.4% of surveyed sites offered home and community integrated palliative care. 25% of surveyed sites reported injectable morphine as only opioid source, which is less feasible to manage severe pain in the home setting.

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Table 1. *Continued*

Reference	Region	Methods	Participant characteristics	Distribution	Finding about opioid availability	
					In hospitals	In home settings
Kamuhabwa and Ezekiel (2009)	Tanzania	Open and close ended questionnaire.	Cancer patients = 200 Doctors = 2 Nurses = 2 Pharmacist = 1 Pharmaceutical technician = 1 Social worker = 1	Ocean Road Cancer Institute (ORCI) in Dar es Salaam, Tanzania. ORCI is the only referral hospital for cancer cases in Tanzania	33% patients were aware of the drugs they were using for pain relief. 4% of the patients were given morphine by injection for several reasons, including vomiting and difficulty in swallowing because of painful ulceration in the throat. 57% patients felt morphine dose was effective to relieve pain. 11% patients felt morphine did not relieve pain. 73% of these patients were given higher dose	Not evaluated

DISCUSSION

The purpose of this review was to appraise the literature on issues in palliative and end-of-life care in Africa in order to determine the optimal setting for palliation of patients at the end of life. Twenty-two articles were included. Many of the articles were used in overlapping categories. The overwhelming majority of articles were qualitative reviews. The majority of literature came from South Africa and Uganda. South Africa's literature tended to be broader whereas most of Uganda's literature focused on its unique public health program. No randomized controlled trials were found and very few data-based studies were found. Overall, the literature on palliative and end-of-life care in Africa was sparse.

Opioid Analgesics

Palliative care largely depends upon the availability of opioid analgesics. The history of opioid availability and usage in Africa has been wrought with inconsistent funding and overall shortages in supply. Studies found that distribution and usage varied by country, site, and primary financial funding. It stands to reason that palliative care can be improved by streamlining opioid availability throughout the continent. However, the literature revealed limitation and barriers that need to be addressed.

Funding

In most cases, availability of opioids in Africa depends upon local funding. Government funding based on official national policy was rare. Two of the eight studies reviewed described the existence of government-funded morphine availability. Clark et al. (2007) reported Uganda as the only African country with a national agenda of supplying morphine. The Ugandan national government has integrated palliative care into health systems at a district level. Because of this, morphine is available in hospitals, hospices, and rural community settings and is prescribed by various healthcare workers, including nurse midwives. South Africa was the only other country to have official governmental financially supported morphine distribution through policy. The drug was found in settings that included hospices, hospitals, and day clinics. Unlike Uganda and South Africa, Kenya has no official palliative care policy, rather the Ministry of Health supplies morphine to Nairobi Hospital, which is supplied by donors from the United Kingdom and the Netherlands.

The predominant source of opioid funding in the 14 surveyed countries comes from NGOs (Clark et al., 2007). Bates et al. (2008) found that in Malawi,

Table 2. *Studies describing caregivers*

Reference	Population	Health professional caregiver	Family caregiver
Whittaker et al. (1991a; 1991b) Frail aged persons residing in South African homes for the aged who requires hospitalization *South African Medical Journal*	South Africa	Hospital workers	Not evaluated
Ndaba-Mbata and Seloilwe (2000)	Botswana	Not evaluated	Range 16–68 years old 12 out of 15 female 66% mothers 60% homemakers with no income Range of ill person 20–39 years old 28% cancer 6.6% diabetes 66.6% AIDS (majority)
Sepulveda et al. (2003)	Botswana Ethiopia Tanzania Uganda Zimbabwe	Nurses provided bulk of healthcare workforce in all 5 countries. 48% of total had no education or primary education only	Botswana: Primary caregiver 100% family member Ethiopia: 80% child or spouse 20% of 80% had no education or primary education only Tanzania: 95% related by blood or marriage Uganda: 86% mother, spouse, or child 74% of 86% had no education or primary education only Zimbabwe: 96% spouse, child, or relative
Lindsey et al. (2003)	Botswana Qualitative study conducted in 3 rural districts within 120 miles of Gabarone. Surveyed caregivers, community home-based care volunteers, non-governmental organization members, social workers, nurses, welfare educators.	Not evaluated	Total caregivers interviewed $n = 35$ Women $n = 32$ Male $n = 2$ Mothers $n = 12$ Grandmothers $n = 7$ Sisters $n = 7$ Daughters $n = 5$ $\geq$54 years of age $n = 19$ (54%) Single $n = 25$ (72%) Female-headed households $n = 23$ (66%) Little or no education 57% Employed outside the home $n = 4$ Caring for HIV/AIDS $n = 15$ Caring for other terminal illness $n = 20$
Uys and Social (2003)	South Africa Descriptive study at 7 sites that integrated integrated community-based home care (ICHC). Urban and rural settings	Only 2 nurses out of 7 hospital and clinic sites were specially trained in palliative care.	Not evaluated
Orner (2006)	South Africa In-depth interviews with primary caregivers >18 years of age.	Not evaluated	Total sample $n = 45$ Average age = 40 Women $n = 43$

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Table 2. *Continued*

Reference	Population	Health professional caregiver	Family caregiver
Sardiwalla et al. (2007)	South Africa Non-experimental design using available hospice workers at 2 sites.	82 hospice workers 92% female 87.2% black average age 33.5 years	Not evaluated
Kang'ethe (2009)	Botswana Qualitative study: 140 registered primary caregivers. 4 CHBC nurses in rural Botswana	4 CHBC nurses in rural Botswana	Age range 18–85 years of age 56% > age 50 98% female 5% tertiary education

the Global Fund, and a nonprofit humanitarian initiative supply morphine. However, Bates et al. (2008) also determined that from 2006 to 2008 morphine was no longer being imported because of inadequate reporting of usage. Data from these reports implicate scattered and unfocused efforts in funding for opioids, leading to inadequate supply and inconsistent availability.

Distribution by Country and Setting

The studies gathered for this review did not include every single African country. A review of the literature revealed the countries where documentation of supply and availability were being evaluated. Table 1 includes these studies and provides the country, location, and type of setting where opioid analgesics were made available to patients. Clark (2007) provided the largest study, cataloging opioid availability in 14 countries. The second most inclusive study was Harding et al. (2010), which included a cross-sectional survey of 14 countries: South Africa, Uganda, Kenya, Zimbabwe, Malawi, Egypt, Tanzania, Nigeria, Botswana, Cote d'Ivoire, Ethiopia, Mozambique, Namibia, and Rwanda. Of these nations, South Africa had the most care facilities with documented distribution of opioids (Harding et al., 2010). According to the reviewed articles, Botswana, Cote d'Ivoire, Ethiopia, Mozambique, Namibia, and Rwanda each had the lowest number of facilities reporting opioid distribution, each with one facility reporting having opioids on site (Harding et al., 2010). The sites included tertiary specialty care facilities such as hospice (35%), NGOs offering integrated services that included palliative care (56.4%), and governmental state network facilities at either a primary or secondary level such as hospitals or clinics (8.1%). The study also found that although the Ethiopian Competent Authority reported opioid availability in the country, the care facilities that were interviewed reported that no opioids were actually available for their patients and none they knew of were known to be found anywhere else in the country. This demonstrates great inconsistencies in reporting and availability that needs to be addressed.

The majority of information on opioid distribution by setting was found at the inpatient level. This included a range of facilities described previously such as hospitals, clinics, and hospices. Beck (1998) found some opioid distribution in hospitals in home-based care; however, nurses, the main providers in community care, were mostly unable to distribute the drug, resulting in lower distribution at the home-based care level.

In general, there was little specific information on opioid distribution in home-based settings. The majority of information simply stated a general the lack of the drug in rural areas without going into further detail. It is important to note that most of the literature on opioid distribution focused on one particular setting or institution. Only three studies included in this review, Beck (1998), Clark et al. (2007), and Harding et al. (2008) specifically surveyed both inpatient and home-based sites within the same study.

Usage

Five of the studies looked at opioid usage solely in inpatient hospital setting and two of those five studies specified hospice or specialized palliative care units. Three of the eight studies examined usage in both hospital and home-based care settings. Opioids were used in all settings; however, the research suggests many barriers to adequate pain management across all settings. One study by Beck and Falkson (2001) evaluated pain levels across various settings and reported that inpatients had highest levels of reported pain. The study determined that 30% of overall patients were not

Table 3. *Studies describing abilities of palliative caregivers to recognize and treat end-of-life (EOL) signs and symptoms*

Reference	Methods	Caregivers studied	Educated on EOL management	Financial limitations	Psychological effects	Transmission risks to caregiver
Schietinger et al. (1993)	Rwanda	Professionals: Trained volunteers	African Red Cross Volunteers interviewed before and 6 months after specific training to care for symptoms of chronic and terminal illness in rural Rwandan villages.	Not evaluated	Not evaluated	Not evaluated
Ndaba-Mbata and Seloilwe (2000)	Botswana 15 family samples who had cared for patient at least 3 months	Family members	Cancer and stroke caregivers informed of diagnosis. HIV/AIDS caregivers not informed. Not taught how to care for symptoms.	Financially draining Huge economic burden	Despondency Hopelessness Social isolation reported as major emotional strain.	Transmission to caregiver: caregivers not education on proper care and risks. Most caregivers not informed of AIDS diagnosis until much later when risk of transmission had been ongoing. Many patients required hospitalization for nausea/vomiting/pain analgesic coverage.
Sepulveda et al. (2003)	Africa Qualitative survey of patients and their caregivers at end of terminal illness of cancer and HIV/AIDS/	Family members	Botswana: Not evaluated Ethiopia: Relief of pain, symptoms, treatment, and drugs needs not being met. Tanzania: Major activities were providing food, drugs, consolation, washing, feeding, clothing.	Botswana: Not evaluated Ethiopia major burdens of caregiver and family were financial, emotional, and anxiety. Tanzania: 45% reported financial constraints in caregiving.	Botswana: Not evaluated Ethiopia: Major burdens of family were emotional, anxiety, fear, sadness. Tanzania: 13% felt drained from patients being short tempered.	Not evaluated

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Table 3. *Continued*

Reference	Methods	Caregivers studied	Educated on EOL management	Financial limitations	Psychological effects	Transmission risks to caregiver
Lindsey et al. (2003)	Botswana Qualitative study conducted in 3 rural districts within 120 miles of Gabarone. Surveyed caregivers, CHBC volunteers, NGO members, social workers, nurses, welfare educators.	Trained Professionals: Volunteers Educators Nurses	Lack of information pervaded. Felt need for more counseling. Felt skills were inadequate to give proper care. ($n = 53$)	Poverty most pervasive theme of study. $n = 69$ Sudden destitution from AIDS/HIV.	Isolation, loneliness $n = 32$ Separated from community Women $n = 56$ reported exhaustion (overriding experience). $n = 26$ reported being overwhelmed. $n = 36$ reported depression. $n = 20$ found religion as comfort but had no time to attend church. Young girls $n = 2$ Exhaustion, difficulty concentrating Psychological trauma, depression-watching family members die	Stigmatization Feelings of being ostracized by community, leading to patients dying secretly.
Uys and Social (2003)	South Africa Descriptive study at 7 sites that integrated ICHC. Urban and rural settings	Trained professionals: Nurses	Urban hospital setting had higher rate of post-test HIV/AIDS counseling than rural sites (55 vs. 8). Lack of adequately trained palliative healthcare workers; gross undermanagement of pain when admitted.	Not evaluated	Most healthcare workers found it difficult to provide emotional care to patients. Spiritual care often provided by healthcare workers.	Not evaluated
Chimwaza and Watkins (2004)	Malawi Qualitative study of 15 caregivers of very sick individuals in rural village of Balaka district.	Family members	None of the patients had formal diagnosis known to caregiver.	Not evaluated	Exhaustion and physical strain	Not evaluated

Orner (2006)	South Africa Interviews with primary caregivers >18 years of age	Family members	Lack of adequate support from community, NGO, government. Felt forgotten.	Disruption of normal working and social patterns. Difficulty trying to work part time.	Reports of negative mental health Despair Stigma a common experience	Gender imbalance 42/45 female caregivers
Rampanjato et al. (2007)	Central Africa Qualitative study of 28 Emergency Department (ED) nurses to observe pain management practices in Central Africa emergency settings.	Trained professionals: ED nurses	25% no formal education on pain management and unable to properly recognize symptoms.	Not evaluated	Nurses reported culture as heavily influencing pain management.	Not evaluated
Sardiwalla et al. (2007)	South Africa Non- experimental design using available hospice workers at 2 sites.	Trained professionals: 82 hospice workers	Workers trained specifically to care for hospice patients.	Not evaluated	Found high levels of stress and burnout could be dealt with at work through meditation, relaxation, and coping exercises.	Not evaluated
Kang'ethe (2009)	Botswana Qualitative study: 140 registered primary caregivers. 4 CHBC nurses in rural Botswana	Family members Trained professionals: CHBC nurses	Most unable to understand definition and process or transmission of HIV/AIDS.	Inadequate sources of income and food. Major stressor for caregiver forced to watch person starve/suffer.	Inadequate community support resulting in psychological neglect and burnout.	Gender imbalance: 98% female caregivers Transmission to caregiver Inadequate sanitation and supplies. Feared bodily fluids. 85% reported lack of available care packages that included bandages, gloves.
Hongoro and Dinat (2011)	South Africa	Trained professionals	Not evaluated	Dying in hospitals avoided additional costs of body storage. Hospital- based palliative care programs reduced hospital congestion.	Not evaluated	Not evaluated

Table 4. *Studies describing use of health care resources for palliative and end-of-life care*

Reference	Place of death	Issues with patients being admitted to hospital at end of life	Availability and usage of hospice	Other significant findings
Beck and Falkson (2000)	Not evaluated	Not evaluated	Availability and usage of hospice evaluated	Hospice patients clearly reported better outcomes: hospice patients had lowest level of "worst pain."
Ndaba-Mbata and Seloilwe (2000)	Not evaluated	Many patients required hospitalization for nausea, vomiting, pain, and analgesic coverage.	Not evaluated	Refer to Table 3
Uys and Social (2003)	52% patients died at home	Caregivers admitted their patient to hospital because: care became too difficult for family caregiver to manage; caregiver felt they had not done all they could until they took their patient to the hospital; certain symptoms that family caregiver could not control difficulty breathing intense pain fistulas and wounds.	Availability and usage of hospice evaluated. 5% of patients died in hospice. Only 2 nurses in 2 sites were specially trained in palliative care.	All patients studied had access to formal regular palliative care services.
Clark et al. (2007)	Not evaluated	Not evaluated	Availability and usage of hospice evaluated.	Not evaluated
Rampanjato et al. (2007)	Not evaluated	Most emergency and acute care, palliative care admissions were for inadequate pain and symptom management in the home-based care setting.	Not evaluated	Refer to Table 2
Lazenby et al. (2009)	36% patients died in home. 18,869 patient death records included in study.	49.7% of hospital deaths were HIV/AIDS related.	Not evaluated	Not evaluated
Alsirafy et al. (2010)	79 patients included; 73% died at home; 27% died in hospital or ambulance. 78 patients included in study.	Not evaluated	Not evaluated	All patients studied had access to formal regular palliative care services. Part of the Egyptian palliative care program provided a triweekly outpatient clinic, 8 bed inpatient unit, and home care service, including regular home physician visits.

receiving adequate analgesics in two South African urban teaching hospitals. An earlier study by Beck (1998) reported poor individualization and incorrect dosing of morphine in South African hospital settings. Alsirafy et al. (2010) reported that only 26% of Egyptian hospice patients requiring strong opioids were adequately covered with appropriate doses.

Similarly, in South African emergency and acute care settings, inadequate pain control was the result of an inability to assess pain properly and therefore manage it appropriately (Rampanjato et al., 2007). In contrast, the administration of continuous morphine was found to be nearly nonexistent in Uganda's public health morphine program because of distances from supplies and financial barriers (Logie & Harding, 2005).

Interestingly, a study in Tanzania implied better breakthrough pain coverage when opioids were managed in a specific palliative care setting rather than a general inpatient unit. Kamuhabw and Ezekiel (2009) found that cancer patients being referring to the Ocean Road Cancer Institute, Tanzania's only cancer referral hospital, for symptoms of end-of-life cancer pain, were treated with both oral and injectable morphine. Of the 200 patients surveyed, 57% in the hospital felt that the morphine dose they received was effective to relieve pain. However, 73% of these patients received higher doses that were reported effective. Similarly, Beck and Falkson (2001) found in South Africa that cancer patients admitted to hospice actually had the lowest level of "worst pain." The study also found that these patients were 30% more likely to receive adjunctive therapies such as sedative/hypnotics, laxatives, topical anesthetics, and anti-emetics. In contrast, however Alsirafy et al. (2010) reported that only 26% of Egyptian hospice patients requiring strong opioids were adequately covered with appropriate doses.

The use of opioids at the community and home-based care level is largely understudied. Organized, statistical data on opioid usage and pain coverage in the home-based setting are severely lacking. No significant improvements were reported in managing pain at the general hospital level over the home-based care level; however, data from inpatient sites were significantly more detailed and thorough than data from home- and community-based settings. Significant differences were seen at the hospice level: studies in Tanzania and South Africa may imply better management of pain coverage in hospice; however, better usage could be attributed to the funding and distribution at the specific sites. Nonetheless, based on the literature, it appears that opioid analgesics are best used to cover pain in a hospice setting.

Nurse Prescribing Privileges

The literature found that Africa greatly lacked qualified opioid prescribers. The literature also found that nurses comprise the bulk of the healthcare workforce in many African countries (Sepulveda et al., 2003). Often, nurses were the only provider that patients came into contact with in both hospitals and rural care settings (Sepulveda et al., 2003). However, nurse prescribing power was generally nonexistent with the exception of Uganda's public health morphine program.

Uganda is the first African country to grant nurses opioid prescribing power as part of its palliative care program for people in the terminal stages of AIDS and cancer (Ramsay, 2003). The government has provided free morphine since 2002, and the majority of patient care, including pain relief, is provided in the patient's own home by specially trained nurses and caregivers (Ramsay, 2003). Unfortunately, training time for nurses is lengthy and expensive. It requires nurses to undergo 9 months of specialty training and tuition. Even nurses who have attained this prescription power report difficulties, such as the great travel distance to patients, and the perceived fears surrounding opioid addiction (Logie & Harding, 2005). The costs barriers coupled with taboos about opioids suggest that Uganda's home-based morphine program may not be the best solution to the palliative care problem.

In addition to a shortage of nurses able to prescribe opioids, Logie and Harding (2005) also documented a shortage of pharmacists to dispense opioid medications. Only 200 licensed pharmacists were counted in Uganda. Furthermore, pharmacists reported inadequate storage space for morphine vials, resulting in stock limitations.

Issues in Caregiving

Description of Caregivers

Evaluating the demographics of caregivers of people at the end of life is important in defining future policy efforts. Eight studies were identified that described demographics of caregivers for the terminally ill toward the end stages of the disease process (Table 2). Four of these studies focused on Botswana, including one study that covered four additional countries: Ethiopia, Tanzania, Uganda, and Zimbabwe. Four of the studies focused on South Africa. Both gender and family emerged as overwhelming themes among caregivers. All of the studies identified women as the primary caregiver in each situation by a large margin. Most of the caregivers were blood relatives. Female relatives with little education in providing care provided the bulk of palliative care in the home. Lindsey et al. (2003) surveyed households in Botswana to determine the primary caregivers and found that 66% of Batswana (the people of Botswana) surveyed households were headed by women. Specifically, these women were the primary caregivers for loved ones with HIV/AIDS at the end of life. Similarly, Nbada-Mbata and Seloilwe (2000) determined that 60% of caregivers, also surveyed in Botswana, were homemakers with no income. Furthermore, Sepulveda et al. (2003), Lindsey et al. (2003), and Kange'the (2009) all determined that >50% of caregivers had little or no tertiary education.

In the hospital, nurses are the majority of professional providers. Sepulveda et al. (2003), determined that nurses comprised the bulk of the healthcare workforce in Botswana, Ethiopia, Tanzania, Uganda, and Zimbabwe. Additionally, Uys and Social (2003) looked at inpatient settings, and determined that nurses were adept in basic care but were by and large unequipped to handle end-of-life cases. Out of seven hospital and clinic sites, only two nurses were specially trained in palliative care.

The fact that Botswana and South Africa were represented in most of the found literature demonstrates the severe lack of evidence for the rest of Africa.

Education on End-of-Life Management

Overall, family caregivers were not properly educated about symptoms related to their patients. Several of the studies cited lack of disease knowledge as a major barrier. Ndaba-Mbata and Seloilwe (2000) described how family caregivers of people with cancer and stroke were informed of the diagnosis but caregivers of people HIV/AIDS were not. In the study by Chimwaza and Watkins (2004) in Malawi, none of the 15 caregivers knew their patients' formal diagnoses and, therefore, had to guess. Kang'ethe (2009) interviewed community home-based care nurses who interacted with family caregivers. The four nurses interviewed reported that families they worked with had a difficult time understanding the definition of HIV/AIDS.

Home care in general was described as basic. Sepulveda et al. (2003), found that, in Botswana, Ethiopia, and Tanzania, home care provided by the family consisted mostly of basic care such as feeding, washing, and clothing. Drugs were only provided by home-based care nurses when available, which was rare. Lindsey, et al.'s (2003) evaluation of Batswana women and young girl family caregivers showed that the majority felt the need for more counseling and that their skills were inadequate to give proper care. Orner (2006) revealed that a sample of selected South African rural family caregivers felt no educational or counseling support from the local community, government, or NGOs that claimed to be supporting them.

Additionally, one study by Uys and Social (2003) showed that both patients and their family caregivers were more likely to receive better education about managing end-of-life care when the education was provided by a hospital. This descriptive study of seven sites that implemented integrated community-based home care (ICHC) compared urban hospitals to rural clinics and communities. Uys and Social found that when offered pre-test and post-test counseling for patients with HIV/AIDS and accompanying caregivers, 55% of the hospital population returned for post-test counseling in contrast to the 8% of rural-based participants who returned for follow-up education. However, a possible explanation for this is the proximity of hospitals in urban settings as opposed to the longer distances individuals had to travel in rural settings. Nonetheless, it suggests that hospitals were more successful at educating patients and their family caregivers.

Additionally, Rampanjato et al. (2007), conducted a qualitative study of 28 emergency setting nurses in Central Africa and determined that 25% of nurse caregivers had no formal education on pain management and were unable to recognize symptoms properly. This, however, is markedly improved from the education reported at the rural and home-based level, suggesting that although need for improvement is evident, hospitals may provide better care of end-of-life symptoms.

Extrapolating from this, it seems that managing symptoms of end-of-life care was quite difficult in the home because of lack of knowledge. Rather than manage pain and other symptoms, caregiving tended to consist of cleaning and bathing the patient to the best of caregiver's abilities.

Effects on the Caregiver

The caregiver experience plays a monumental role in palliative care. Whether the caregiver is a health professional or family member, studies have shown the negative financial, psychosocial, and health impacts caregiving can have on the family member or professional providing that care (Orner, 2006; Manicom, 2011). Also, evidence has shown that education and preparation has a varying impact on the way professional and family caregivers are able to tolerate their stressors (Ndaba-Mbata & Seloilwe, 2000). Ten articles were found that provided great detail on the efforts and limitations of care providers (Table 2). All of the studies were qualitative studies that relied on interviewing and questionnaires for data collection.

Financial limitations. Providing care was generally found to be economically devastating on the family caregiver. Lindsey et al. (2003), found poverty to be the most pervasive theme for women and young girls caring for loved ones at home. The study's feedback specifically pointed out the "suddenness" of destitution from providing care to loved ones with HIV/AIDS. The devastating effects of economic hardships included lack of food, water, and supplies to nourish other healthy household individuals. Sepulveda et al. (2003) surveyed participants in Tanzania and found that 45% of caregivers felt financial constraints from caregiving.

Hongoro and Dinat (2011) was the only study that looked at financial effects of South African hospital-based palliative care programs. The study analyzed costs from a program that was based in a large teaching hospital but provided community outreach while incorporating hospital visits, and, in many cases, admissions for end-of-life cases. The study determined that poverty levels made dying at home unsuitable and that dying in hospitals avoided additional costs such as body storage. Furthermore, it concluded that having specially trained palliative care teams reduced hospital congestion and freed beds for other critical cases.

The prevailing themes arising from financial hardship single out the devastating effects of abrupt destitution, and the disruption of normal working patterns. The evidence suggests that specially trained palliative care teams are not only better for the patient, yet perhaps better financially. Also, the literature suggests that hospitals with special hospice teams may reduce costs and save resources.

Psychological effects. Negative psychological effects prevailed in home care of the terminally ill. The most commons findings were hopelessness, stigmatization, and isolation. Three studies specifically demonstrated a high incidence of loneliness from social isolation. Lindsey et al. (2003) described caregivers and patients being separated from the community and lacking group support. Sepulveda et al. (2003) found that in Tanzania, 13% of caregivers felt drained from their loved ones being short-tempered. Lindsey et al. (2003) found that young girl caregivers felt exhaustion and had difficulty concentrating in school and were traumatized by watching their loved one die slowly. Overall, depression was a common finding resulting from loneliness and burnout.

Stigmatization was described in at least two of the studies. Orner (2006) described this as a common experience by caregivers of loved ones with HIV/AIDS in South African homes. Additionally, Lindsey et al. (2003) reported women and young girls feeling so ostracized that at times patients were left to die secretly, hidden from the community. In comparison, Rampanjato et al. (2007) determined that most hospital emergency department nurses surveyed admitted to cultural influences, specifically noting taboos surrounding opioid use, in the way they managed their patients.

Spirituality emerged in several studies as a coping method. However, in home care, Lindsey et al. (2003) found that although women found religion a great comfort, most had no time to attend church because of the great responsibilities of caring for a sick person. In contrast, Uys and Social (2003) found that in South African hospitals, healthcare workers reported some ability to provide religious and spiritual care, although privacy was their main reported barrier.

Sardiwalla et al. (2007) studied the effects of stress on a sample of South African hospice workers, which concluded that the majority of stress was work related and could be dealt with through meditation, relaxation, and coping exercises.

The findings suggest that home-based and rural caregivers are not equipped to address the spiritual and psychosocial needs of both themselves and their loved ones. Caregivers at home were overwhelmingly affected negatively, the majority of psychological damage being reported in home-based care. Whereas the literature reported stress and burnout among acute care and hospice workers, findings indicated that stressors tended to be specifically work related and manageable within the workplace.

It stands to reason that hospitals and clinics could benefit from having hospice units that provide spiritual care that aligns itself with the models of palliative care for the sick and dying.

Transmission risks and other findings. Transmission of HIV/AIDS and safety risk were highest in home-based care. Most common reasons cited were lack of knowledge pertaining to transmission routes and proper cleaning care. Kange'the (2009) surveyed 140 caregivers in Botswana and found that 85% of community and home-based care nurses reported lack of available supplies to prevent transmission from bodily fluids. Ndbaba-Mbata and Seloilwe (2000) determined that caregivers were not educated on transmission risks, and that several family caregivers did not even know routes of fluid transmission. No literature was found on transmission risks in hospitals.

Use of Healthcare Resources for Palliative and End-of-Life Care

Healthcare resources were evaluated by looking at places of death, issues with patients being admitted to the hospital at the end of life, and the availability of hospice.

Place of Death

Four studies were included in this review that focused specifically on places of death in Africa (Table 4). One study, by Lazenby et al. (2010), looked at place of death (home or hospital) in Botswana. The study sampled 18,869 death records received from the government's Registry of Births and Deaths (RBD). Lazenby determined that home deaths accounted for 36% of all sampled Batswana deaths and that 49.7% of hospital deaths were from HIV/AIDS-related causes.

The other three studies that evaluated places of death in Africa surveyed patients who all had access to formal, regular palliative care services in both inpatient settings and the home. Uys and Social (2003) looked at patients in seven different sites participating in ICHC, a model in South Africa that links hospitals, clinics, and home-based care. Patients in ICHC are provided counseling, regular home care, and terminal care. Uys and Social found that 52% of patients surveyed in South Africa died at home. Similarly, Alsirafy (2010) revealed in his study of 78 patients enrolled in the Egyptian Palliative Care program, 73% of patients died at home and 27% died in the hospital or ambulance. The study looked at patients enrolled in a program that provided a tri-weekly outpatient clinic, access to an eight bed acute care facility, and weekly visits from physicians in the home. Lastly, Manicom (2011) studied places of death among patients with cancer under the care of the Constantiaberg Oncology Unit in Cape Town, South Africa. Patients in this retrospective 3 year study were specially referred to a palliative care cancer program. In the sample of 424 deaths, 42.92% patients died at home, whereas 34.2% patients died in an acute care medical facility. The remainder of surveyed patients died in unknown locations.

The evidence strongly suggests that more patients are likely to die at home when they have regular, adequate access to palliative care. More research is needed on public health records in order to gain a better sense of overall trends in places of death. It is important to note the difference in sample sizes as well. The three studies that found home deaths to be a majority ranged from sample sizes of 79 to 424, whereas Lazenby et al. (2010) surveyed a sample size of >18,000 deaths.

Issues with Patients Being Admitted to Hospital at End of Life

A large number of patients are being admitted to hospitals for unmanageable symptoms from HIV/AIDS and cancers during the end stages of the disease. Patients at the end of life used hospital resources largely when symptoms became too difficult for caregivers to manage in the home. Symptoms leading to hospital admission included difficulty breathing, intense pain, multiple fistulas, and wounds. Ndaba-Mbata and Seloilwe (2000) reported that many patients required hospitalization for nausea, vomiting, and analgesia. Rampanjato et al. (2007) also found that most emergency and acute care setting palliative care admissions were the result of inadequate pain and symptom management in the home.

Manicom (2011) evaluated the length of hospital stay for patients with cancer at the end of life being admitted to an acute care oncology ward. Thirty-eight percent of patients admitted to the acute care oncology ward were in the hospital for ≤ 3 days before dying. Additionally, 15% of patients being admitted died the day of admission. Manicom attributes these end-stage admissions to the possibility that urgent or alarming symptoms may have developed at the end of life causing caregivers to bring their patients to hospitals for immediate attention. An additional speculation is that these organized home palliative care services still fail to prepare adequatelyall their patients for death at home.

Availability of Hospice

Overall, the research showed that when hospice was available, it was used. Uys and Social (2003) surveyed only 5% of patients being admitted to hospice. However, in the survey of seven sites, it was found that only two nurses in two sites were specially trained in palliative care.

Studies indicated that when hospice was used, symptom management was generally good. Beck and Falkson (2001) determined that hospice patients had the best controlled pain when compared with those in other inpatient units and community settings.

There was reported delay between when patients submitted hospice forms to when services commenced. Some individuals preferred not to have contact with hospice even in the face of terminal illness (Manicom, 2011).

There were no studies found in this review that specifically detailed the existence of inpatient hospice units, and it was generally concluded that lack of funding inhibits further development of inpatient hospice units.

Recommendations

Based on evidence from the literature, it is recommended that both governmental and nongovernmental funding be based on the proximity to inpatient facilities. Large urban areas should focus on developing inpatient palliative care and hospice units. Evidence shows that the highest availability of opioids occurs in inpatient facilities. Furthermore, the literature demonstrated superior pain management with inpatients, specifically in hospice. Focusing efforts on specialized palliative care units may also reduce the burden on family caregivers. Trained professionals are better equipped to handle the psychological stress of palliative caregiving than are relatives in the home. Even though professional caregiver burnout was a notable issue found in the literature, lobbying for workplace counseling to improve coping may be easier when financial funding and policy is focused on developing specific hospice units.

Optimal settings for palliative care delivery have been wrought with inconsistencies. Proponents of rural community-centered palliative care are driven by the assumption that most people at the end of life who suffer greatly reside in the country, far from urban settings (Sepulveda et al., 2003). Africa has a long history of rural, agrarian livelihood. However, although many Africans still identify strongly with a rural way of life, it is a fact that Africa's population is becoming increasingly urban as population expands (Donnelly et al., 2005). Studies analyzing census data agree that urbanization is a relatively recent phenomenon in Africa (Collinson et al., 2007). This wave of migration began in the post-colonization era and has continued at a rapid rate. Africa's urban centers have grown despite the shrinking economy, largely because, despite poor living conditions and being far from home, individuals can still make more money being close to a major urban center than in the country (Bryceson, 1996). Given this, funding and research priority should be given to specialized inpatient units in urban areas that will likely see immense patient volumes as urbanization rapidly expands.

For a large number of patients at the end of life in need of palliative care, hospitalization is not a feasible option, given the distance, transportation, time, and money required. Therefore, in rural areas where there is little or no access to hospitals, it is recommended that home-based palliative care teams be formed with nurses having the ability to prescribe opioids and other adjunctive medications. Current limited research shows nurses' hesitancy to prescribe based on cultural fears and general lack of support from other healthcare providers. There needs to be more research on the nurse prescribing training program that is part of Uganda's free public morphine program. It should be evaluated whether or not the lengthy and expensive training program actually teaches responsible prescribing or just serves as an additional barrier. The restrictions on nurses' prescription power are shortcomings in palliative care efforts, as the benefits of nurse prescribing seem to outweigh concerns. There is no evidence of nurses or caregivers abusing opioids in the palliative care setting, and, therefore, this should not be considered an influencing factor when allocating funds and resources to the development of home-based palliative care services.

Finally, home-based palliative care teams in rural areas should focus on counseling and education for family caregivers. The literature revealed that family caregivers, who consisted primarily of female relatives, were alarmingly uneducated about their loved ones' diseases. Furthermore, family caregivers were not aware of proper sanitation precautions. If palliative care funding moves forward in a home-based care model, it is imperative that family caregivers be educated on the risks and proper care techniques for minimizing those risks. This is essential in reducing transmission and addressing the burden of HIV/AIDS that plagues Africa.

CONCLUSION

Overall, the 22 articles included in this review demonstrate a slow start to the great need for palliative care research in Africa. Based on the evidence, it seems that focusing funding on inpatient hospice is ideal in urban hospitals where patients can access facilities. This seems more beneficial than sending staff out to homes where resources, reporting, and research tend to be more scattered. In areas where access to inpatient facilities is not feasible, nurse opioid prescription power is the first-line recommendation, followed by focused education and counseling for female family caregivers. Studies directly comparing opioid distribution and "good deaths" by site are greatly needed. In general, further research evaluating the efficacy of Africa's palliative and end-of-life care programs is required in order to strengthen conclusions on optimal settings for end-of-life care.

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