

Africa: Diversity and Development

Untreated Pain at End-of-Life: Experiences of Family Carers Who Oversee Home Death in Rural Sub-Saharan Africa: A Historical Narrative Review of the Qualitative Literature

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Competing Interest Declaration- Prologue

I am not a medical person or an academic. A voice from the community of Africa's frontline informal family carers of the terminally-ill, I nursed my mother in an African village and witnessed her dying process in my first death management experience. While caregiving in a modern facility in New Zealand shortly afterwards, I anticipated seeing dying people writhing and croaking in death-throes. But I observed a different manner of dying. As death happened, I questioned why my mother died so violently for 27 hours, and decided to educate myself on Sub-Saharan African palliative care.

A. INTRODUCTION

1. The Need for Palliative Care and How People Die

Palliative care is meant to improve the quality of life of patients and families in the face of life-threatening illness. It is designed to provide relief from pain and other distressing symptoms. Palliative care is equally intended to support families to cope during the patient's illness and through bereavement (World Health Organisation: Palliative Care). Considered fundamental to health and human dignity, palliative care is a basic human right, which, under article 12 of the International Covenant on Economic, Social and Cultural Rights, and article 7 of the International Covenant on Civil and Political Rights, obligates countries to ensure that patients have its access, alongside pain treatment (palliative-care-human-right).

People die differently. Some, experience intense pain, restlessness, chest rattling, nausea and shortness of breath (<http://www.bpac.org.nz/BPJ/2011/june/lcp.aspx>). Witnessing such symptoms, untreated, may raise great concern in those attending to the dying person. According to Sherwin Nuland, many deaths are painful experiences for the dying individual and their family, with less than one in five people likely to die easily via an undisturbed coma ([how-we-die-by-sherwin-b.html](http://www.bpac.org.nz/BPJ/2011/june/lcp.aspx)).

Complimentary to palliative care, the Liverpool Care Pathway for the dying patient (LCP) is planned to help doctors and nurses provide quality End-of-Life care options for patients in the final days or hours of life. LCP provides comprehensive symptom control guidelines for the management of the five main end-of-life symptoms: pain, restlessness/agitation, respiratory tract secretions, nausea, and dyspnoea (<http://www.bpac.org.nz/BPJ/2011/june/lcp.aspx>).

2. Home-Based Care for the Terminally-Ill in Sub-Saharan Africa

Realising their great inability to handle widespread AIDS-related morbidity, the public sectors of most poor HIV/AIDS highly affected countries shifted the focus of clinical care from formal health services to the community in mid to late 1990s (Ogden, Esim, & Grown, 2006). This

placed the care for the dying, squarely in the hands of family members, with the potential for managing home deaths.

Palliative care research is driven by the large number of people who need the service. By the close of 2013, eighty percent of the estimated global 20 million people who needed palliative care resided in low and middle-income countries (WHO, EB134/28). In Sub-Saharan Africa, palliative care is essential for people grappling HIV-related illnesses, cancer, Non-Communicable Diseases, an ageing population and some communicable illnesses (Gysels, Pell, Straus, & Pool, 2011; Sepulveda et al., 2003; AIDS Epidemic Update-UNAIDS, 2001; Namisango et al., 2013).

3. Study Aim and Objectives:

While affirming the work of various studies on the needs of carers of the terminally-ill in Sub-Saharan Africa, this private study was conducted to seek comprehensive insight into the progressive status of Sub-Saharan African palliative care, to determine its capacity to inhibit pain at the end of life and to promote the welfare of carers of the terminally-ill, including their overseeing of home death. I attempted to depict and gauge the scope of rural Sub-Saharan Africa's palliative care environment and pain relief. I explored views on 'good or bad death', caregiving experiences and community responses to caring needs. My paper answers the following key questions:

- i. What kind of palliative care conditions exist in rural Sub-Saharan Africa?
- ii. Where are rural Sub-Saharan Africa's terminally-ill and dying people cared for?
- iii. Who takes care of the terminally-ill and dying in rural Sub-Saharan Africa?
- iv. What are the caregiving needs and challenges of rural Sub-Saharan Africa's carers?
- v. What kind of support exists for rural Sub-Saharan Africa's carers?
- vi. What are the factors of a palliative-care-promoted 'good death'?
- vii. Discussing death and dying during Sub-Saharan African terminal illness: what is said?

4. The Nature of the Reviewed Studies

The scope of the reviewed literature covered integrated health systems, education and training, medicines and research policies and practice as hallmarks for adherence to the World Health Organisation Public Health Approach (WHO, EB134/28, 2014). The extent to which such principles exist would either inhibit or promote prospects for patients to die in untreated pain, with implications for carers.

Ten articles were analysed. Three studies covered carer matters (Kipp, Tindyebwa, Rubaale, Karamagi, & Bajenja, 2007; Powell & Hunt, 2012; Streid et al., 2014). One article (Sepulveda et al., 2003) went beyond carer issues, to examining health system capacities regarding patients' and families' quality of life in five African countries. At the centre of Sub-Saharan Africa's palliative care is contending pain, which is experienced throughout the HIV disease trajectory, peaking at the end of life, when around 80% of both cancer and AIDS patients get moderate-to-severe pain (WHO, EB134/28, 2014). Four studies focussed on the role of pain relief in palliative care (Grant, Murray, Grant, & Brown, 2003; Vogel, 2011; Merriman & Harding, 2010; Harding, Powell, Kiyange, Downing, & Mwangi-Powell, 2010). Two studies examined palliative care research in the African context (Gysels et al., 2011; Namisango et al., 2013).

5. Methods

a) Geographical Coverage

While secondary data sources embraced a wider scope of Sub-Saharan Africa (Harding et al., 2010; Gysels et al., 2011; Powell & Hunt, 2012), reviewed primary studies were conducted largely in Eastern Africa, which had enjoyed greater research activity over the past decade (Namisango et al., 2013). For such advantage, Eastern Africa was considered

better placed to provide an overview assessment of Sub-Saharan African palliative care development. The reviewed primary studies were carried out in Kenya (Grant et al., 2003), Uganda (Merriman & Harding, 2010; Kipp et al., 2003) and Rwanda (Vogel, 2011), as well as in the country-set of Botswana, Ethiopia, Tanzania and Zimbabwe, (Sepulveda et al., 2003). One primary study expanded the scope beyond Eastern Africa to include South Africa (Streid et al., 2014).

b) Reviewing Method, Articles Selection and Data Analysis

The reviewing involved summarising and critiquing bodies of literature and drawing conclusions, as well as identifying gaps and inconsistencies in the bodies of knowledge under scrutiny, in line with Cronin, Ryan, & Coughlan, (2008). The contributions of individual studies on the topic were analysed thematically and with regard to methodological issues. The study took the historical orientation to enable understanding of present-day Sub-Saharan African palliative/End-of- life care in the context of the programme's evolution, tied within an era.

All studies were located in Sub-Saharan Africa and focused on palliative or End-of-Life care with at least one of the following Keywords: Policy; Terminal Illness/Disease; HIV/AIDS; Cancer; Pain; Death/Dying; Home-Based Care; Traditional/Rural; Good or Bad Death; Carer Needs Challenges/Stressors; and Carer Coping Strategies. Thematic matters determined by the study objectives, weighed against World Health Organisation (WHO) Public Health Approach ideals of integrated health systems, education and training, medicines, and research policies (WHO, EB134/28) were loaded onto colour-coded tables for analysis. Endnotes were used to track referenced articles and later edited to remove repetitions.

B. RESULTS

1. Sub-Saharan African Palliative Care Conditions

a) Palliative Care Environment: Integrated Health Systems Scope

Studies that were done prior to 2003 revealed that African healthcare services provided little or no palliative care for the chronically-ill, despite the need, with a very high shortage of healthcare professionals (Sepulveda et al., 2003; Kipp et al., 2007). Where palliative care was available, healthcare fees were prohibitive for the poor. Out of the five countries that took part in the WHO Africa project on palliative care, only Botswana had an operational home-based care programme which was integrated into the national health system (Sepulveda et al., 2003).

Palliative care remained patchily covered by 2007 (Harding et al., 2010) It was still described as a piecemeal matter by 2011 (Gysels et al., 2011) and largely not included in governmental policy and planning (Namisango et al., 2013). Although nine sub-Saharan African countries with no known activity/capacity building had moved to a status of isolated provision by 2011 (Namisango et al., 2013), culturally appropriate, holistic integrated palliative care services were still rare, even by 2012 (Powell & Hunt, 2012).

In 2011, Rwanda planned to provide countrywide high-quality, affordable comprehensive palliative care by 2020 (Vogel, 2011). By 2013 many palliative care units had opened under Eastern African governments, alongside increased research outcomes, particularly in Uganda and Kenya (Namisango et al., 2013). By the close of the review period palliative care remained inaccessible to the vast majority, inspiring the description: 'at best limited, and at worst non-existent' (Streid et al., 2014).

b) Palliative Care Environment: Education, Training and Research

At the start of the review period, carers lacked resources and skills to handle patients with various difficult symptoms, with one study mentioning that dealing with impending death was

dreaded (Grant et al., 2003). Patients and carers decried scarce personnel to administer medication (Sepulveda et al., 2003).

Health professionals largely lacked palliative care knowledge, exhibited little interest in dying patients and refused to prescribe medication for children amid myths of opioid addiction, well beyond the middle of the reviewed period (Harding et al., 2010; Gysels et al., 2011). Despite the need for training, Powell & Hunt (2012) doubted the standard of training fit for all stakeholders against the nature of challenges that beset the Sub-Saharan African palliative care climate, which basically only allowed delivery of a highly diluted manifestation of palliative care. Research activities were reportedly minimal and deficient in methodological strength up to the end of the review period (Gysels et al., 2011; Powell & Hunt, 2012; Streid et al., 2014). Despite the odds, by the close of the review period, four Eastern African countries of Kenya, Uganda, Tanzania and Zambia were offering palliative care education at certificate or diploma level, with Uganda making the milestone of delivering university level palliative care education (Namisango et al., 2013). However, clinicians interested in doing research in Eastern Africa still faced high clinical workloads by the end of the reviewed period (Namisango et al., 2013).

c) Pain Relief Programme Scope

Prior to 2003, drug policies were largely restrictive and ineffective while essential drugs proved unaffordable when available (Sepulveda et al., 2003). Despite medical specialist shortages such as in Uganda, only medical doctors were allowed to prescribe strong pain medication like morphine (Sepulveda et al., 2003). By 2007 HIV/AIDS antiretroviral drugs were allegedly equally rare and costly (Kipp et al 2007). While Uganda introduced affordable oral morphine at household level in 1993, less than a quarter of African countries accessed morphine seventeen years later, because of restrictive legislation and bureaucracy (Merriman & Harding, 2010). Across 12 Sub-Saharan African countries by 2010, pain relief management failings were seen to promote suffering, while opioids programme expansion was still reliant on the coping ability of ailing regulatory bodies, thwarting the feasibility of further pain relief growth (Harding et al., 2010). Carers' inability to provide sound care was also linked to lack of access to appropriate pain relieving drugs due to restrictive protocols (Powell & Hunt, 2012). Despite such shortcomings, the Rwandan government's intention to provide nationwide comprehensive palliative care with pain relief by 2020 served as an unprecedented African palliative care milestone (http://pdf.usaid.gov/pdf_docs/pnaed053.pdf; Vogel, 2011).

2. The Place of Care

Apart from one article (Gysels et al., 2011), all studies that covered the place of care identified the home as the place where Sub-Saharan Africa's terminally-ill resided, even when some established formal healthcare was received alongside homecare (Grant et al., 2003).

Home-based care was apparently recognised as the only feasible means of providing adequate access to palliative care (Sepulveda et al., 2003). It was identified as the model of choice of palliative care delivery in Sub-Saharan Africa (Powell & Hunt, 2012). The home was acknowledged as the place "where the majority of rural African people still die" (Grant et al., 2003:165). Essentially, opioids provision extension to where people needed the service was desired since it was not possible for specialist hospice services to accommodate all patients requiring palliative care (Harding et al., 2010). Particularly in Uganda, patients reportedly preferred dying in their own homes (Merriman & Harding, 2010).

3. Carers of the Terminally-Ill and Dying in Rural Sub-Saharan Africa

Sepulveda et al., (2003) and Grant et al., (2003) informed that family members provided care for the terminally-ill. Carer composition was described as mainly elderly women and young girls (Kipp et al., 2007); old and young women (Powell & Hunt, 2012), or older women and

young people (Streid et al., 2014). One review study established that carers were mostly women and children, with only one study allegedly refuting the assertion (Gysels et al., 2011).

4. The Care Environment: Effects of Untreated Pain on Patients and Carers

Before 2003, patients with great need of pain and other symptoms relief, called for accessible, affordable drugs, (Sepulveda et al., 2003; Grant et al., 2003). Around the same time in Meru, Kenya, the effect of severe unrelieved pain caused trepidation for death and the dying moment in some patients, while such turmoil prompted suicidal thoughts in others (Grant et al., 2003). By 2010, Merriman & Harding (2010) credited morphine to controlling severe pain in advanced cancer, asserting that it promoted happy, pain-free and peaceful dying experiences. However, they also acknowledged that morphine was not the drug of choice for all kinds of pain.

This review showed that intense psychological suffering from relentless patient pain caused families to suffer and panic (Merriman & Harding, 2010; Streid et al., 2014). According to Grant et al., (2003), failure to relieve severe patient pain and other symptoms had a deep negative effect on some carers, prompting anxiety and helplessness to the point of suicidal thoughts. Principally, witnessing the suffering of loved ones constituted an extreme stressor, causing carers to feel inadequate, helpless and frustrated (Streid et al., 2014).

5. The Care Environment: Patient and Carer Needs

Issues that caused the most distress to patients were identified because the environment of their care was deemed to have a bearing on the care burden. Prior to 2003, terminally-ill people needed financial support and alleviation of social, emotional, and spiritual problems (Sepulveda et al., 2003; Grant et al., 2003). Meanwhile, failure to discuss emotional issues such as the fear of death, anger and bitterness, frustration, depression and loneliness, was itself identified as a barrier to wellbeing because it restricted revelations that might lead to better care, including pain relief (Grant et al., 2003). In underscoring the significance of pain and its relief, Merriman & Harding (2010) assumed that a patient in severe physical pain would not be able to appreciate a care package inclusive of psychological and spiritual attention, until their pain was relieved. Ultimately, Merriman & Harding (2010) described pain relief as the cornerstone of palliative care.

According to this review, carers were troubled by financial limitations, emotional and physical conditions (Sepulveda et al., 2003; Gysels et al., 2011), as well as social and economic concerns (Kipp et al., 2007). Grant et al., (2003) figured that the lack of knowledge and skills of caregiving and the privation of care-enabling facilities and resources translated caring into an overwhelming experience. Despite providing total care for the terminally-ill in the home, carers lacked support from professionals or the extended family, rendering caring tasks a huge burden (Gysels et al., 2011; Powell & Hunt, 2012). Carers desired in vain, for friends and family to visit, encourage and assist them with hands-on and material aid (Kipp et al 2003). One study proposed that stigma towards HIV/AIDS-engineered illness without psychological burden support increased the stress of caring (Gysels et al., 2011). Despite such trials in care provision and the need for evidence-base to address the deficits, very little research allegedly existed on the End-of-Life care needs of patients and their carers (Gysels et al., 2011).

Different studies brought unique insight to the needs of carers. Kipp et al., (2007) depicted a picture of the vulnerable position of family carers in the formative stage of End-of-Life care intervention. They uncovered a tremendous gender-based care burden and sacrifices, which were entirely unacknowledged in HIV/AIDS programming or national HIV/AIDS planning. In this review, their study was instrumental in defining such complex care burden as needing interdisciplinary attention and intervention, rather than from Ministries of Health alone. In their study of End-of-Life experiences in Meru, Kenya, Grant et al., (2003) observed that

patients, carers and faith organisations needed various support as death approached. They recognised the need to help families to identify appropriate carers because not everyone was cut out to be a carer. They also brought to light, the finding that some families dreaded the impending terminal stage when death would eventually arrive, and they could not handle the hard situation. Streid et al., (2014) revealed that Sub-Saharan African carers faced a complex and delicate interplay of challenges described as a care burden comprising primary and secondary stressors, mediated by internal and external resources. They also made the novel discovery of the potential of a failed resource to turn into a stressor, with detrimental consequences on carers. In the discussion of caring from the age and gender perspectives, Powell & Hunt (2012) described the cost of caring as mostly difficult for elderly women carers, who usually took charge of caring for their sick adult children and orphaned grandchildren.

6. The Care Environment: Community Responses to the Care Burden

Grant et al., (2003) found that some patients ascribed great value to the support of close family relations and the care shown by local communities and faith-based organisations in meeting emotional, social, and spiritual needs. On the contrary, Gysels et al., (2011) reported of a debilitating effect of the AIDS pandemic on traditional African extended family coping support system. Kipp et al (2007) similarly found inadequate support from friends, neighbours and even close family, leading to isolated families grappling the care of a directly related patient. The situation was interpreted as the HIV/AIDS pandemic dictating new family dynamics that challenged traditional family structures and eroded predictable patterns of behaviour (Kipp et al., 2007). Conversely, Powell & Hunt (2012) concluded that even if evidence suggested that patients and families were sometimes rejected on moral grounds, most people dying from AIDS in Africa continued to receive social care from their families, friends, and communities.

7. Factors of a Palliative-Care-Promoted 'Good Death'

Studies that dealt with the concept of a 'good death' took a firm stand on this End-of-Life care matter. Sepulveda et al., (2003) described as tragic, the human suffering associated with HIV/AIDS and cancer noted in Africa that lead to deaths accompanied by suffering that could be avoided or relieved if adequate palliative care were provided. It was considered unacceptable to die in overwhelming pain, abject poverty, loneliness and isolation (Grant et al., 2003; Vogel, 2011). In contrast, Merriman & Harding (2010:7) placed the use of morphine to control pain in advanced cancer at the heart of a highly effective and cost efficient model of care that made it possible to "humanely manage the problems of those with terminal illness, and to offer a culturally appropriate 'good death'".

8. Discussing the Subject of Death during Sub-Saharan African Terminal Illness

Grant et al., (2003) found that HIV/AIDS stigma and cultural sanctions deterred patients from discussing their illness. Patients and carers were not eager to discuss the nature of the illness, fearing severe witchcraft reprisals. Besides HIV/AIDS stigma, the fear of informing family members that patients had a long-term disease that would probably drain family resources, equally promoted the silence (Grant et al., 2003). Similar remarks were cited by Powell & Hunt (2012) who, especially viewed the culture of silence as linked to issues of morality and infidelity which was exclusive to heterosexual couples, alongside taboos on discussing sex in Sub-Saharan Africa. In one study incidence, while speaking of severe unrelieved pain, patients alluded to the prospect that pain might be unbearable as death approached, causing dreadful thoughts for the dying moment and even fleeting suicide contemplation (Grant et al., 2003). Carers' feelings about the imminent death of their charges were thus, only fleetingly covered.

9 Researchers' Policy Recommendations

a) Recommendations on Palliative Care

Before 2003 studies urged integrated healthcare systems and whole-family focused 'total care' that embraced physical, economic, social, spiritual, and psychological support- tailored to the cultural and social context of local communities (Sepulveda et al., 2003). Researchers also stressed pain relief and total 'coping care' rather than aggressive curative care, urged help for families to identify relations suited for the role of carer, and promoted open discussion of illness diagnosis and prognosis between medical staff and patients (Grant et al., 2003).

After 2003, researchers advocated for holistic, harmonious and complimentary changes in integrated health systems to remove unnecessary suffering (Harding et al., 2010; Merriman & Harding 2010). They promoted good deaths for everyone (Vogel, 2011) and urged the improvement of policy and legal frameworks (Merriman & Harding 2010; Vogel, 2011; Harding et al., 2010). Researchers envisioned changes in programmes administration (Harding et al., 2010; Vogel, 2011), in resources availability (Harding et al., 2010) and progress in pain relief provision- extended to rural areas and home-based care services (Harding et al., 2010). Studies called for cheap, quality and effective appropriate palliative care and pain relief (Merriman & Harding, 2010; Vogel, 2011). Models of care and drug options relevant to local contexts for those in need were endorsed across Africa (Merriman & Harding, 2010).

Researchers encouraged a combination of advocacy, education and training to guarantee and sustain good pain relief and ensure educated stakeholders across the board (Merriman & Harding, 2010; Harding et al., 2010; Vogel, 2011). The incorporation of palliative science into all levels of healthcare training was advised, to improve clinical practice (Harding et al., 2010). Those who had witnessed pain relief change were implored to share their experiences with those still struggling to initiate care packages (Merriman & Harding 2010).

b) Carer Issues Recommendations

Studies backed lessening the impact of HIV/AIDS on carers by strengthening caregivers' capacity to meet the challenges of care- raising awareness, preventing carer burnout and promoting training in basic nursing and counselling skills (Kipp et al., 2007; Powell & Hunt, 2012; Streid et al., 2014). More involvement of men and boys in care provision was supported to impede carer fatigue (Kipp et al., 2007; Powell & Hunt, 2012). The focus on tackling the needs of entire family units rather than just individual patients, in line with the holistic requirements of the WHO palliative care approach, which was stressed by the WHO Africa Project on palliative care back in 2003 (Sepulveda et al., 2003) was echoed in the middle, and at the close of the period under review (Kipp et al., 2007; Streid et al., 2014). Fortification of the role of faith-based institutions for spiritual and other care support was recognised (Kipp et al., 2007; Powell & Hunt, 2012). Governmental and nongovernmental agencies, were advised to give carers widespread support by embracing a joint approach to carer help and recognising the multidimensional nature of the carer burden (Kipp et al., 2007; Streid et al., 2014).

Persuaded by the effect of patient pain on caring capacity, Powell & Hunt, (2012) proposed that family carers get increased reasonable access to effective pain relief medication under adequate safety measures. In recognition of the role of family caregivers in promoting medical, social, and economic wellbeing, and against the challenges they faced, Kipp et al., (2007) suggested that HIV/AIDS programmes take responsibility for, and adopt family caregivers as their legitimate clients in HIV/AIDS policies and plans.

10 Researchers' Recommendations for Further Studies:

Conceding limitations due to novelty in their fields of enquiry and restricted study breadth, researchers urged further studies to compare their findings (Sepulveda et al., 200; Grant et al., 2003; Gysels et al., 2011; Streid et al., 2014). Research was deemed desirable in identifying the needs of terminally-ill patients and their carers, and on gaps in care and

culturally appropriate care models specific to given environments (Sepulveda et al., 2003). Grant et al., (2003) proposed studies into patient restrictions on illness discussion, while Powell & Hunt (2012) promoted research on the emotional and spiritual impact of family caring, as well as the feasibility and effectiveness of the pilot project started in Uganda that authorised the prescription of opioids by nurses (Sepulveda et al., 2003).

Gysels et al., (2011) promoted further research into the scarcely researched field of socio-cultural End-of-Life care needs of patients and their carers, particularly outside of South Africa, as well as on HIV/AIDS stigma towards patients and carers. Even if researchers only slightly disagreed on the preferred place of care, amid the complex contextual nature of the matter, Gysels et al., (2011) called for more evidence on the place of care preference and its determinants. Despite the high incidence of mortality in Sub-Saharan Africa, Gysels et al., (2011) detected scarce evidence on grief and bereavement, as only three studies represented the bereavement process in their review. At the close of the review period, Namisango et al., (2013) promoted diversification of research attention to other aspects of palliative care, noting that pain relief had been the object of much research with successful results in Uganda. As the first study to examine the carer burden in incurable, progressive disease in Africa, Streid et al., (2014) urged further investigation in different populations to broaden understanding of carer experiences. They also encouraged studies into consequences of the care burden with regard to carer depression and anxiety, the possible benefits of caregiving, and examining in greater depth, the ways in which faith communities, spiritual beliefs, and family/community relationships affect the caregiving experience (Streid et al., 2014).

11 Researchers' Methodological Contributions

Individual articles brought different aspects of methodological benefits to the review. Harding et al., (2010) pointed out the logistical hardships of conducting research in resource-poor communities of Sub-Saharan Africa, with the potential to impact upon response rates. Gysels et al., (2011) observed the need for studies to incorporate voices from the wider community, thereby situating End-of-Life care within the local social and cultural context. They also observed that ethnographic studies in cultural issues were inclined to be more informative and enabling of culturally sensitive interventions. While recognising the presence of exceptions, a lack of methodological robustness in palliative care studies was a common observation by researchers under review (Gysels et al., 2011; Powell & Hunt, 2012; Streid et al., 2014).

C. DISCUSSION OF THE MAIN FINDINGS

1. Sub-Saharan African Palliative End-of-Life care Conditions

a) Palliative Care Environment: Integrated Health Systems Scope

High disease burden spanning the review period sustained a high need for palliative care in Sub-Saharan Africa (Sepulveda et al., 2003; Gysels et al., 2011; Vogel, 2011; Merriman & Harding, 2010; Streid et al., 2014). Although studies have increasingly ascertained the need for, and identified the type of care needed, Sub-Saharan African palliative care remained largely irregular, inaccessible, unaffordable (Sepulveda et al., 2003; Harding et al., 2010; Gysels et al., 2011; Vogel, 2011), unintegrated (Powell & Hunt, 2012) and non-inclusive (Namisango et al., 2013). While these results concur with the classification which placed Botswana, Ethiopia and Rwanda under patchy/isolated palliative care; Kenya, South Africa, Tanzania and Zimbabwe, apparently reached preliminary integration into mainstream service provision, showing a variety of palliative care providers and types of services, despite their limited influence on palliative care policy with Uganda providing advanced mainstream integration level services (WHO, Global Atlas of Palliative Care at the End of Life, 2014).

b) Palliative Care Environment: Education, Training and Research

Lack of palliative care awareness and skills among health professionals and local communities was a common observation (Grant et al., 2003; Sepulveda et al., 2003; Harding et al., 2010; Gysels et al., 2011; Powell & Hunt, 2012). By the close of the period however, Kenya, South Africa, Tanzania and Zimbabwe were linked to increased awareness of palliative care among both stakeholders (WHO, Global Atlas of Palliative Care at the End of Life, 2014). Ultimately, these countries provided substantial numbers of training and education initiatives by a range of organisations, even up to university level in Uganda, alongside interest in the concept of national palliative care associations.

Research on palliative care appears to be a fairly recent undertaking in Sub-Saharan Africa. One of the earlier reviewed studies referenced articles going back barely 25 years, with only 4 out of seventeen reference study sources used, being on palliative care in Africa (Grant et al., 2003). Sustained descriptions such as 'lacking sound evidence', 'minimal publications' (Gysels et al., 2011; Namisango et al., 2013), and 'dearth of empirical data' (Harding et al., 2010; Streid et al., 2014) reveal a tone of researcher dissatisfaction with the state of Sub-Saharan African palliative care research across the review period. However, Namisango et al., (2013) show that providing evidence-base does pay off, as demonstrated by significant palliative care growth alongside earnest research activity in Uganda and Kenya.

c) Pain Relief Programme Scope

Despite noted deficient palliative care knowledge which persisted across all stakeholders, affecting attitude and practice including further opioid expansion (Grant et al., 2003; Sepulveda et al., 2003; Harding et al., 2010; Gysels et al., 2011; Powell & Hunt, 2012), this review noted one success story. The Ugandan programme of affordable morphine at household level was a major Sub-Saharan African palliative care milestone (Merriman & Harding 2010), placing it alongside the best performing countries, globally (WHO, Global Atlas of Palliative Care at the End of Life, 2014). Although failings in other policies initially thwarted its replication elsewhere, the availability of morphine and other strong pain-relieving drugs appears to have considerably improved in Kenya, South Africa, Tanzania and Zimbabwe (WHO, Global Atlas of Palliative Care at the End of Life, 2014). While Rwanda pledged to provide inclusive palliative care with pain relief by 2020 (Vogel, 2011), it maintained an isolated palliative care provision category alongside Botswana and Ethiopia, with limited availability of morphine by the close of the review period (WHO, Global Atlas of Palliative Care at the End of Life, 2014).

2. The Place of Care

Apart from one study, all other studies in the review reported on terminally-ill patients who resided mainly at home (Grant et al., 2003; Kipp et al., 2007; Powell & Hunt, 2012; Streid et al., 2014). In a study of patients and carers on predominantly homecare, Grant et al., (2003:165) forthrightly acknowledged 'the home' as the place "where the majority of rural African people still die". With the single study that contended the place of care endorsing the assessment of care needs from a 'household perspective' (Gysels et al. 2011), Sub-Saharan Africa's terminally-ill were effectively deemed as cared for at home.

3. Carers of the Terminally-Ill and Dying in Rural Sub-Saharan Africa

The reviewed studies largely identified women and girls as family carers of the terminally-ill in Sub-Saharan Africa (Sepulveda et al., 2003; Grant et al., 2003; Kipp et al., 2007; Powell & Hunt, 2012; Streid et al., 2014). The composition of family carers, analysed against the burdensome nature of the work environment, ideally renders caregiving a gender-and-age discriminated matter (Kipp et al., 2007; Powell & Hunt, 2012).

4. The Care Environment: Effects of Untreated Pain on Patients and Carers

The impact of patients' untreated pain on carers and how carers coped with the circumstance was essential to this study. Throughout the review, studies depicted patients contending overwhelming pain (Sepulveda et al., 2003; Grant et al., 2003). Severe unrelieved pain caused trepidation for the dying moment, prompting suicidal thoughts (Grant et al., 2003). Relentless patient-pain caused family panic and suffering (Merriman & Harding, 2010; Streid et al., 2014). Failure to relieve severe patient-pain caused family and carer anxiety, helplessness, suicidal thoughts (Grant et al., 2003) inadequacy and frustration (Streid et al., 2014).

These outcomes of this review, mirror the January 2014 Human Rights Watch findings in India, Kenya, Mexico, Senegal, and Ukraine whereby patients suffered pain so severely that they became suicidal or attempted suicide (un-who-boosts-hope-pain relief). While the reviewed articles did not discuss death and dying amid pain, it is suggested elsewhere that with sudden deaths from conditions like heart attacks declining and life expectancy growing, death has been rendered a long-drawn-out process for many people (Lynn & Adamson, 2003; and Kass, 2005; in Carey, 2008). Against such background, and with Sherwin poignantly describing the great majority of deaths as painful experiences for both the individual and their loved ones (how-we-die-by-sherwin-b.html), it is highly probable that protracted home death poses challenges for those who oversee it. Elsewhere too, death attending-nurses needed to be prepared for the death-throe phase, calming families and medicating patients to hinder the effects of air hunger, (Tarzian, 2004). Such scenario may suggest high panic levels in both the patients and attending family members, warranting specific procedures. While the reviewed studies advocated pain relief up to household level, the situation of those who die without pain relief was not the object of examination.

5. The Care Environment: Carer Needs

Notwithstanding the positive emotional, social and spiritual aspects of met care needs (Grant et al., 2003; Powell & Hunt, 2012), this review found that carers of the terminally-ill generally faced a complex care burden (Grant et al., 2003; Powell & Hunt, 2012; Kipp et al., 2007). Carers' repeated calls for different kinds of assistance, including knowledge and care skills, revealed a need for carers' support and instruction in all aspects of care, throughout terminal illness (Sepulveda et al., 2003; Gysels et al., 2011). Ultimately, the combined analysis of the unanimous conclusion on care providers and the nature of their work conditions as presented by Kipp et al., (2007) and Powell & Hunt, (2012), fundamentally renders caregiving a gender-and-age discriminated matter. Despite the need, crucial analytical research evidence was lacking (Gysels et al., 2011; Streid et al., 2014). Essentially, even within the focussed aspects of care needs, researchers' concerns stopped short of the most certain and dreaded outcome of terminal illness care: handling the death process.

6. The Care Environment: Community Responses to the Care Burden

The review found evidence of patients who received significant support from close family relations, local communities and faith-based organisations. However, others got little or no support, citing failures in the dynamics of African traditional coping systems which had been eroded by widespread demands of HIV/AIDS (Gysels et al., 2011; Kipp et al., 2003). Mutually overtaken by frustrating and financially draining long illnesses, African families failed to look out for one another. While part of the solution towards carer and family support is locked up in out-of-reach economic empowerment, re-ignition of the African sense of belonging and social responsibility, regardless of widespread morbidity may hold the key to ensuring support.

7. Factors of a Palliative-Care-Promoted 'Good Death'

Dying in crushing pain, abject poverty and isolation is perceived as 'not dying well' (Grant et al., 2003; Vogel, 2011; Sepulveda et al., 2003). Morphine reportedly facilitated "culturally appropriate 'good death' (Merriman & Harding, 2010:7), while suffering in pain, robbed carers and patients of the 'dignity of life and death' (Merriman & Harding, 2010:7). This

underscores the vital role of pain relief in determining a 'good death', but which still eludes many. Likewise, protracted painful death remains a reality even in western countries because nature rarely delivers the desired idealised easy end, while not even medical science can guarantee it (http://develpsych004.webs.com/documents/Chapter_19.pdf). Ultimately, the very prevalent belief that a peaceful death is possible, is considered unattainable and a fallacy, as, ideally, the great majority of deaths are painful experiences for both the dying and their loved ones ([how-we-die-by-sherwin-b.html](http://develpsych004.webs.com/documents/Chapter_19.pdf)).

8. Discussing the Subject of Death during Sub-Saharan African Terminal Illness

This review found nothing about taboos on discussing the experience of overseeing the dying process. Although some patients imagined agonizing pain as death approached, (Grant et al., 2003) carers' thoughts on imminent death and their readiness to handle it, were not followed through. While HIV/AIDS stigma and cultural sanctions prevented discussion of illness, it remains unsaid if the same factors would inhibit death-experience dialogue among carers. While the need for pain relief is well documented, little is said about painful dying and the implications for family carers dealing with the situation in rural Sub-Saharan Africa. However, such uncanny silence around death and dying is not an isolated case. The concepts of death and dying have intimidated even the medical fraternity with textbooks seldom making reference to them (Carey, 2008). Elsewhere, adults facing terminal illness candidly avoided talking about death, instead, using substitute expressions, such as 'passing away,' 'going out,' or 'departing' (http://develpsych004.webs.com/documents/Chapter_19.pdf).

9. Researchers' Policy Recommendations- Palliative Care and Carer Issues

The desire to change Sub-Saharan African palliative care for the better is reflected in the recommendations made across the review period. Different studies submitted endorsements which were linked in purpose by special thematic similarities that uniquely mirrored identified shortfalls. Across the review period, studies urged a holistic boosting of integrated health systems, education and training, medicines and research policies. Researchers repeatedly urged strengthening of caregivers' capacity to meet the challenges of care.

The decade-long researchers' concerns and recommendations were echoed in the 2014 WHO palliative care resolution (palliative-care-human-right), which compelled all countries to eradicate needless pain suffering, develop national palliative care strategic plans, integrate national public health systems, eliminate regulatory barriers to essential palliative care medication and to incorporate palliative science into healthcare professions' training (WHO 467 palliative care resolution). In both cases, the recommendations counter similar challenges that insistently hamper quality palliative care provision. Such persistent recognition of the same global palliative care challenges across the board raises questions about compliance on palliative care resolutions implementation over time, which essentially maintains situations that leave patients and carers vulnerable to the consequences of untreated pain at end of life.

10. Analysis of The Research Agenda Recommendations

Only one study made a slight reference to untreated pain at end of life. Grant et al., (2003) observed that dying in untreated pain was undesirable, imminent home death was dreaded, and that patients, carers and churches needed different kinds of support as death approached. However, the researchers did not discuss the issues in detail or propose them for further study.

11. Methodological Gains From This Review

All the reviewed articles were qualitative studies. Most likely, few rural Sub-Saharan African communities would have complete listings of terminally-ill populations to support quantitative paradigms. Ethnographic studies were hailed for the study of culture specific issues in Sub-Saharan Africa (Gysels et al., 2011), while caution and care in the choice of data collection

methods to promote response rates in resource-poor communities was raised (Harding et al., 2010). During this study, the use of colour-coded text for each article proved an excellent way to spot similarities and differences within thematic tables and in the report.

12. Limitations of the Analysed Studies to Adequately Inform This Review

Although the reviewed studies met their objectives in addressing different aspects of palliative care, they were not focussed on overseeing home death overshadowed by untreated pain. The reviewed studies served as a starting point into a hardly covered field in Sub-Saharan Africa. Yet, even such sources may not be representative of the average African scenario, in that more than half of the countries used in the study hold higher-end palliative care provision classifications (WHO, Global Atlas of Palliative Care at the End of Life, 2014).

13. Limitations of this Review to Adequately Inform

Seeking insight into palliative care for personal catharsis, addressing a wide range of issues was a demanding and complex undertaking that was executed with limited resources, including access to significant databases. Ultimately, rather than uncover the experiences of carers overseeing home death dominated by untreated pain, the review has succeeded in illuminating a vacuum that surrounds the last act of terminal care.

D. CONCLUSION

Throughout this review, scholars have pointed out similar problems hindering Sub-Saharan African palliative care efforts. While similar issues have dogged Sub-Saharan African palliative, there appears to be significant increase in researcher ability to spot, describe and analyse generally similar palliative care challenges, with suggestions for their correction.

This review shows that Sub-Saharan African Palliative care has seen some growth in terms of national palliative care policies development, service integration and scale-up, alongside research activity and palliative care education- particularly in Eastern Africa. Pain relief has made huge strides in Uganda where oral morphine has been taken to poor rural households, with the highest health system integration of Level 4b (WHO, Global Atlas of Palliative Care at the End of Life, 2014). However, while significant growth has been registered in such isolated cases, similar palliative care challenges have largely persisted elsewhere, hindering services delivery, chiefly pain relief. Dying in severe pain is perceived as bad death. Examined alongside the WHO 467 Palliative Care Resolution, Sub-Saharan African palliative care capacity to promote good deaths and the welfare of family carers at end of life remains limited.

Largely older women and girls provide home-based care for the terminally-ill and dying-under immense challenges of physical and socio-economic deprivations, with little or no support from family or local communities. Caregiving is a gender-and-age discriminated matter. HIV/AIDS stigma and cultural sanctions deterred patients from discussing the illness. While the general experiences of carers for the terminally-ill across the terminal stage are backed by research, a knowledge void surrounds family carers' experiences of managing home death.

a) What Do The Findings Confirm?

These results validate the WHO opinion that many nations still struggle to ensure responsive health policies, limiting pain relief and health professionals' availability, while research and training remain inadequate (WHO, EB134/28). Against such background, the prospects for protracted dying and the implications for compromised welfare of home death attending carers is highly probable. Ultimately, securing global pain-free deaths remains outstanding. Although the experiences of informal carers in Sub-Saharan Africa are under-researched (Gysels et al., 2011), different aspects of family carers' experiences through terminal illness

care are known, while the needs of carers during and beyond the death of their patients, including the overseeing of home death are not known. Within the socio-economic status quo, supporting patients and carers in various aspects, including managing home death appears to be the most feasible option for promoting a dignified last experience in rural Sub-Saharan Africa.

b) What Needs To Be Done About The Revelations?

My study affirms and brings under one umbrella, the work done to unravel the physical, emotional, psychological and socio-economic needs and challenges of rural family carers in Sub-Saharan Africa. Having highlighted the lack of evidence around untreated pain and home death and the likely consequences for carers under such circumstances, this study directs focus on this critical issue, which adds closure to the process of End-of-Life care experience. After showing carers' need of instruction in skills for their tasks over the terminal trajectory, I consider investigation of the needs of home death management as equally essential. The fact that every End-of-Life experience concludes in death, regardless of the patient's status of pain, or location, underscores the need for enabling family carers to oversee home death.

Future Research Agenda

To the best of my knowledge, and within the confines of this review, no study investigated or recommended research into untreated pain at end-of-life, to identify and describe the needs or challenges of family carers who oversee home death in Rural Sub-Saharan Africa.

Regardless of the lack or level of palliative care given, every patient ultimately dies. This study considers as a necessary research area, the period overlapping the death process, which essentially lends closure to the caring journey.

I urge practitioners and academics to conduct death studies in different culture-specific rural Sub-Saharan African settings to record whatever knowledge may be held in oral traditions on how family carers are coping with managing home death. Besides finding out what carers and communities may already know about coping with their challenges of care, it is important to find ways to re-ignite Africa's dying sense of community and social responsibility- which money cannot buy or drugs fill in.

The many questions which this study triggered in me may raise interest for further contemplation on untreated pain and home death management:

1. How could Africa's sense of belonging and social responsibility around terminal illness within the current socio-economic deprivations be re-ignited?
2. What really propels the total package of 'bad death' as in 'death throes'? Does the 'death-throes' experience solely occur on account of high level pain experienced during the course of illness? Or, would the death-throes experience not occur in chronically ill patients who do not experience any pain during the course of illness?
3. What would be the implications for overseeing home death for family carers in rural Sub-Saharan Africa such as in Meru, Kenya, against the background of culturally-held beliefs that saw death as a source of uncleanness, physically, and spiritually dangerous to the health of the clan (Grant et al., 2003), especially with poor knowledge surrounding the infectious nature of HIV/AIDS? The Lozi people of Barotseland apparently share similar dogmas that call for the cleansing of all people who attend a burial, without necessarily having 'touched' the deceased.
4. If the stigma of the shame around HIV/AIDS prevented both patients and carers from discussing the nature of the patient's illness (Grant et al., 2003), would the stigma of the

shame around HIV/AIDS equally impact upon the carers' ability to talk about any challenges experienced while their loved ones went through the dying phase?

5. Even with the best of intentions, death ultimately comes to every patient, underscoring the necessity of opening dialogue into life's only definite conclusive event. Would talking about the looming death and its process, thereby boosting knowledge and skills in its management- benefit carers and help them to cope better with home death challenges?
6. In the light of the admission that morphine is not the treatment of choice for all pains (Merriman & Harding, 2010), how are rural Sub-Saharan African patients and carers coping in situations where the current pain relief regimen is inadequate? Essentially, is the Sub-Saharan African End-of-Life care pain relief package able to rid poor rural households of painful home deaths?
7. One family found the prospect of death 'too hard' to contend with. "When he became too ill, we were not able to face the end. The mouth stayed open, and he could not eat, nor swallow anything. The eyes stayed fixed. The young children of the compound kept calling for Granddad. We were so afraid of his death, so we borrowed money for the vehicle and took him to hospital" (Grant et al., 2003:162). What are rural Sub-Saharan African carers of the dying at home witnessing? What aspects of the dying process do family carers find most challenging? How do carers who oversee home death without any choice, cope with the experience?
8. In the face of noted significant care burden, where would rural Sub-Saharan African family carers prefer their patients to be cared for and to die?

Epilogue

This self-education has given me a great sense of relief- knowing that many people struggle as they care for dying family members and learning about family responsibilities and the goodwill of the international community. However, this kind of knowledge and the practical outcome of research undertakings is not readily available at grassroots level. It is important to get both current and future knowledge to carers and the community because it will empower them.

This scholarly work is a private undertaking, executed without any academic entity affiliation. I thank my friend Lim Hioki Im for proofreading the report and my siblings for their inspiration.

Following this, I want to conduct a field study to find out what family carers who oversee home death in rural Sub-Saharan Africa are seeing and how they are coping.

Dedication

This work was conducted to the memory of my Mother: Bo Ma-Mundia Inonge Simasiku: 13-06-1930 to 09-04-2010, with the promise to make things better for others.

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