

Review Article

Open Access

Unnecessary Suffering in the Developed World from Cancer and Life Limiting Illnesses for Lack of Adequate Pain Control Training for All and Fear of Opioids Lessons from African Palliative Care

Dr. Anne Merriman MBE¹, FRCPI, FRCPEdin, MSc (IntComHealth) and Eve Namisango² Msc, PhD

¹Founder, Director of Policy at Hospice Africa, Uganda

²Programmes and Research Manager, African Palliative Care Association

SUMMARY

This paper gives examples of palliative care as it is today in some areas of UK, USA and Ireland. It also gives the story of oral morphine suitable to LMIC's because it is a simple formula that is affordable and so easy to make even at the kitchen sink! This can change the suffering of millions of those suffering from cancer and other pains at the end of life, allowing the carers to address the Total Pain described by Dame Cecily Saunders that also can increase the physical pain and distress, for patient and family, at this special time of life.

*Corresponding author

Professor Dr. Anne Merriman, Founder, Director of Policy at Hospice Africa, Uganda. Tel: +256 759267488; Email: annemerriman313@gmail.com

Received: December 12, 2022; **Accepted:** December 19, 2022; **Published:** December 24, 2022

Introduction

While I have been helping the suffering in Africa for 42 years I realize that, even now, those in my dear homelands and in many developed countries, with cancer and other life limiting diseases are still suffering even more, due to lack of basic information on pain control, fear of opioids and misuse of analogues for pain [1]. This, combined with delays in referral to palliative care, as even many doctors think that palliative care should be delayed until the end. This misinformation is transmitted to families of these patients [2]. Yes, these countries have palliative care, but pain relief experts seem to be confined to palliative care services [3]. These services are recommended to be introduced to a patient as soon as a life-threatening illness is identified [4]. But in these countries referral to palliative care services are blocked by primary care and specialist doctors until the patient is very close to death [2]. The amount of suffering in this time is huge.

Evidence from Patients and Families

Story 1: "I would rather die than let that pain come back" but it kept coming back....

A relative of author 1 in Ireland, had been diagnosed with adrenal cancer and with disseminated secondaries, remained in severe pain for almost a year before he passed. I was privileged to be with him for a couple of days at home and to visit him, just before his death in a private hospital. I witnessed his terrible bouts of pain, as the opioid analogues prescribed, wore off.

The last time I saw him in the private hospital he confided in me "I would rather die than let that pain come back". The family had asked for palliative care and the oncologist refused until his last days of life. When the palliative care consultant was brought in, my cousin's wife told him, that Uganda and some countries in Africa are now relieving severe pain in Africa within 24 hours and was given with all the safeguards and regulations in place.

By using a simple and affordable formula of oral morphine, they could die at home in comfort with their families, (where most would like to die). This caring palliative care specialist admitted that he was ashamed..... of the situation in Ireland.

Story 2: "the Primary Health Doctors were afraid to touch oral morphine!" in the country where this was researched and proven non addictive in 1967 by Dame Cecily Saunders. UK. A friend had been working with Hospice Africa in Uganda where we have complete pain control for those referred to palliative care at Hospice Africa since 1993. She returned to UK with severe abdominal pain. This pain progressed and primary doctors were unable to identify the cause. Under the NHS there is a long wait for investigations and there was need for an abdominal scan. The primary health care doctors tried to control pain using many different morphine analogues, afraid to touch morphine but the pain continued, and the side effects caused by these analogue medications were sometimes worse than the pain!! On one occasion she was given large doses of Pregabalin which caused severe Parkinsonian like tremors and caused her to fall in the street. She was very aware that her pain was not neuropathic, but she was no longer a health professional but a "patient" and was expected to do what she was told!

But the waiting list was long for a scan, the only way to identify the cause was to go privately. Friends contributed to have this done and it was found to be due to cancer. Three months later after further investigations surgery was done. It was only post-surgery that the pain was completely gone. But in those 3 months the pain had been excruciating. The friend (now the patient) knew that this could have been completely controlled with oral morphine which cannot give addiction as it is not possible to give IV in the dilutions available for use.

Story 3 (US)

“If only we had known about Palliative Care from the beginning, the quantity of time may have been less, but we could have had some fun times” Jack was 62 when diagnosed with stage 4 prostatic cancer. He and his wife had planned an extensive journey for his long-awaited retirement at 63. Now all their plans were turned into looking for a cure for Jack. He was pushed through every kind of oncologist who then referred him to another. The couple were so sad to be missing the visits to their grandchildren in their travel camper and the visits abroad they had planned which had now come to a screeching halt. Nobody asked Jack what he wanted to do or saw the damage being done to his quality of life. They did not even tell Jack about the Palliative Care Team. With the advice of all the oncologists Jack had surgery, radiation, and chemotherapy. When one treatment did not work another was tried, even to the extent of traveling all over the USA to seek another opinion, another treatment. This went on for 5 years until finally there were no more treatments to offer him. He and his wife were miserable those 5 years, everything they had planned evaporated before their eyes.

With nothing more to offer, Hospice and Palliative Care were discussed with Jack and his wife. For the last 5 months of his life Jack’s wife and the Hospice and Palliative Care Team made him comfortable. If Palliative Care had been offered to Jack when he was first diagnosed could he and his wife have had some of their retirement wishes fulfilled? Jack and his wife asked this question often,” If only we had known about Palliative Care from the beginning, the quantity of time may have been less, but we could have had some fun times”

Discussion

Here in Africa, we find this occurs, but it is because they had never heard of palliative care until recently and still do not see it as a specialty bringing comfort and pain relief in all aspects to the patient not only facing the end of life but also suffering excruciating pain. Time and time again we hear of stories from friends whose relatives have died suffering needlessly back in our home countries. This is now occurring in the country where Dame Cicely Saunders introduced modern palliative care with complete pain control to the world in 1967 following her research in St Joseph’s Hospice in London and commenced in St Christopher’s Hospice. This is available today and palliative care education is available now in many countries [5]. Yet primary health and other specialist doctors, are not practicing or teaching pain control [6]. Human Rights watch declared in 2000 that doctors who did not relieve pain when the medications are available can be considered as torturers!

Uganda since 1993, and other African countries are now making oral morphine, from a simple formula and with all controls in place [7]. Uganda is now doing better than the very countries where palliative care and specialist pain control commenced in 1967 [8]. The “magic” medicine, morphine, that is given orally, at very low cost and free to all when prescribed by a registered doctor or nurse prescriber, can completely relieve the severest of cancer pains, bringing the patient to peace and sometimes back to independence [7]. They could also make plans for their families after they had gone. Our biggest problem is that we are only reaching 14% of those in need who are lying in their own homes. We need more Nurse clinicians, fully trained in palliative care to reach all. Several have already completed, and others are in progress towards, a Masters’ degree in African palliative care from the Institute of Hospice and Palliative Care in Africa (IHPCA) at Hospice Africa Uganda. But Nurses salaries are very low, and many cannot afford to pay for tuition. We need scholarships for education.

This service is available to even the poorest of households through the palliative care teams in regional hospitals, and from small voluntary Hospices, and is reaching 90% of the Districts in Uganda. Sadly, as only 14% of those in need are receiving this care, we are not far from global unmet estimate of 1 in 10 people accessing palliative care [9]. Too many of those making decisions think that “West is best!” and continue the myth that PC should not be brought in until the very end is near. But our health professionals have still to learn that African problems need African solutions, and we have the solutions in African Palliative Care. How did this formula for affordable and culturally acceptable morphine, come to Africa yet is not known world-wide?

The Story of Affordable oral Morphine Solution

In 1984, author 1 was working in Singapore. A specialist in Geriatric medicine and palliative care, she was then a Senior Teaching Fellow (equivalent to Associate Professor) working in Community health department at National University of Singapore. Following a Master’s degree in International Community Health, she was invited there because Singapore at the time found that their population pyramid was standing on its head. This was due to a government ruling that education would only be free to 2 children per family. Any family that had more than 2 children would have to pay for the third child on, for education. So as the elderly were increasing the populations of the future who should be supporting them was decreasing! It was brought to the attention of Government that there was need now to have carers for the elderly population which was now greater than the younger population. Thus, the University was looking for someone to guide them on how to treat and support the elderly population while they considered expanding education to more children per family, thus Encouraging expansion of the under 15’s.

I was a clinician and especially interested in care of the elderly and palliative care for those approaching death. On consultation in the hospitals, I could see that Singapore had greater treatment for cancer than UK and US at the time, but when there was no sign of cure the patient was told “nothing more to do” and was sent home without adequate pain control. I, was given the opportunity to speak to medical teams and found that so many nurses were then upset with this situation, having learnt the conditions of the patients being sent home without home support. We suggested commencing a home care team and asked for volunteers. I had four dedicated nurses to work with me for the next 5 years. We all visited the homes, after our working hours and at weekends, as our job descriptions did not allow home care (or for me clinical work unless for research) in working hours. Initially we found that some patients were screaming ceaselessly with severe pain. The population was only 2.5M but living on an island 22 by 11 miles. Most of the population lived mainly in high rise flats. This suffering was frightening for family and neighbors equally.

Morphine powder was available in Singapore, but the only formula was for Brompton Cocktail [10]. This formula was adjusted to the country using it and usually contained as well as morphine, cocaine, alcohol (in the form of the local brew) and chloroform water. The Cocaine and chloroform water were excluded early on, but the local brew continued in most countries and other additives included sedatives such as chlorpromazine, according to perceived patient needs. Thus, the patient was drowsy from all the additives. It was then difficult to tell if the morphine dose was controlling the pain or was too much, as the sign for too less is persistent pain and for too much is drowsiness!

We needed a pure solution of oral morphine, so we sat down with the pharmacists at the National University Hospital, kindness of the Chief Pharmacist at that time (Mr Liak Teng Lit) and together with Dr Cynthia Goh, we came up with a formula containing morphine powder, water, a preservative. With this we were able to control pain in almost all cases by titrating pain needs with relevant analgesic the morphine was titrated against the pain until the patient was free of pain, not drowsy and able to think clearly. We registered more than 400 patients seen at home in the next 3 years without addiction or diversion. Some even were able to return to work while on their morphine.

I left for Nairobi in 1990. But going for interview in 1989, I had brought them a copy of my book “International Geriatric Medicine”, with teaching programs and formula for our oral affordable morphine [11]. I really wanted to join the team at Nairobi Hospice, but I told them I would not come without oral morphine being available. Professor Kasili, Chair of the Board of the new Nairobi Hospice, approached the Government and had the powder imported. Morphine was constituted initially in the pharmacy at Nairobi Hospital. It was available and being used when I returned to take up position of Health Services Coordinator (Medical Director) at Nairobi Hospice in June 1990.

During my time in Singapore, my main mentors and advisors were Geoffrey Hanks then head of PC in the London Cancer Hospital (the Brompton Hospital), and colleagues at the Walton Pain Unit in Liverpool. From this article by Hanks I have continued to teach that M6G is more potent than morphine itself, both in pain relief and sustainability in the system [12]. When morphine is taken orally then it is mainly metabolized in the liver through the digestives system where morphine is metabolized into M6G (at that time considered 47 times more potent than morphine) and M3G which is virtually non-potent for pain control. When given parenterally the morphine goes directly to the renal system and is excreted with only a small amount reaching the liver. IV morphine has a much shorter half-life. A larger percentage is excreted directly through the kidneys, thus when given therapeutically it tends to reach a ceiling so fast, giving rise to demands for higher doses for break through pain. When given sub cutaneous, it is more effective but M6G conversion is still much less than when given orally, reducing in half-life due to excretion through the renal system by passing the liver. (Figure 1 here)

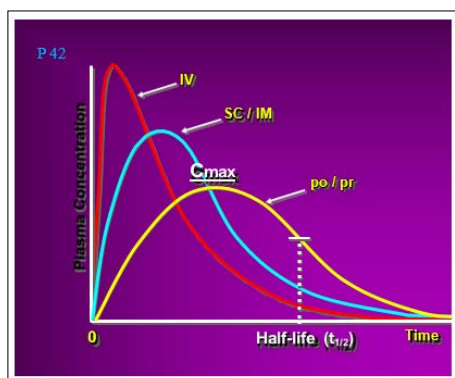


Figure 1

This is also showing that smaller doses of oral morphine will control pain, giving permanent pain control, when taken regularly at the correct dose, than parenteral morphine. The experiments described this in a more recent pharmacological study used 90mgs daily doses in strong young men [13]. We commence on 2.5-5mgs daily orally which is a total of less than 30 mgs per day and often

get initial response within 4 hours. However, the initial dose is increased according to the intensity of the pain. (See Figure 2 by AM)

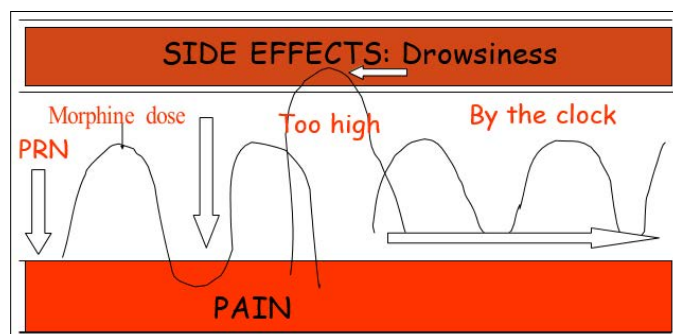


Figure 2

We must remember that chronic pain and its management are very different to supporting a patient through cancer pain or even an HIV patient through the pain of an inter current infection with severe pain such as cryptococcal meningitis. We have managed HIV patients before ARVs were available and we managed to withdraw the morphine gradually, if the infection resolved, without any problems. Chronic pain which is not going to resolve, has real problems with possible addiction and needs for increasing doses due to tolerance giving rise to increasing doses. This is usually managed by anaesthetists in their Pain Clinics.

Discussion

Although pain control is possible in African countries since 1990, it is still difficult in many of the developed countries. Fear of morphine addiction has recently been increased due to publications from US. US needs to remember that no two countries are the same, in economy, culture, social situations and medical knowledge. The increasing addiction problems in US are not repeated here in Uganda, where we have treated approximately 35,000 patients with oral morphine solution since 1993 [14]. We have found no addiction or diversion with oral solution. All the legal safeguards are in place and families are instructed to keep the bottle out of the reach of children [7].

US has veterans from the wars in Vietnam and more recently Afghanistan, where armies underwent really difficult situations while fighting and tortured when taken prisoner. In these situations where opioids are easily available, they reach out for something to calm their minds and allay their guilt when forced to take actions against their beliefs and sensitivities. Many of these continue an addiction lifestyle, as veterans, particularly when unemployed. There is also a culture among the young teenagers that smoking pott etc. is “cool.” Some crave for it so much that they are building up a cohort of addicts

We have had to do much advocacy to persuade Government departments, the police, and particularly senior doctors, who are not aware of the history of palliative care and safe use of oral morphine. This has brought Uganda to reach where we are today with palliative care services available in the home in up to 90%of Districts [15]. The oral solution is free to all who are prescribed by a recognized registered prescriber. This has been proved to give continuous pain relief in most cases, while under the care of palliative care teams. The recent letters sent to WHO, condemning their publications introducing the use of morphine for cancer and other causes of serious physical pain need to be re-edited and published again. WHO have also for many years declared that morphine is the best and most affordable analgesic? Many

of these publications have backed up our advocacy in different African countries. The withdrawal of some of these has done further damage to our attempts in advocating for morphine use.

End Note

This is a plea for availability and use of oral morphine in serious pains in cancer and other acute conditions including sickle cell disease, burns, A&E etc. We also call for further training of doctors and nurses both in hospitals and primary care, to never leave a patient in severe pain, which has been known, worldwide, since 1967, thanks to Dame Cecily, how to manage such pains. Let not our hospitals and primary care services be seen as torturers because of lack of education, and their fear of morphine. We all need to be aware of the side effects of less potent and more dangerous analogues that only increase the suffering for many. This includes families who must watch the suffering and suffer with their loved ones. Morphine, which comes from the poppy flower, is a God given medication to relieve pain. It is our responsibility to manage suffering not just with medicine but with empathy and support, for a high quality of living, at this precious time of life.

Acknowledgements

To family members in cases 1&2 and to friends of family in case 3. Without their sharing their stories, we would not have witness to examples of uncontrolled suffering in our developed world, which we care for so much in spite of dedicating our lives to Africa.

References

1. Knaul FM, Farmer PE, Krakauer EL, LD Lima, A Bhadelia et al. (2018) Alleviating the access abyss in palliative care and pain relief-an imperative of universal health coverage: the Lancet Commission report. *Lancet* 391: 1391-454.
2. Low D, Merkel EC, Menon M, E Loggers, H Ddungu et al. (2018) End-of-Life Palliative Care Practices and Referrals in Uganda. *Journal of palliative medicine* 21: 328-34.
3. Kagarmanova A, Mwesiga MD, Sisk ML, C Kabagambe, S Nyakaisiki, et al. (2022) Palliative care in Uganda: quantitative descriptive study of key palliative care indicators 2018-2020. *BMC Palliative Care* 21: 55.
4. WHO. Palliative care. 2020. <https://www.who.int/news-room/fact-sheets/detail/palliative-care>.
5. Rawlinson F, Gwyther L, Kiyange F, Luyirika E, Meiring M, at al. (2014) The current situation in education and training of health-care professionals across Africa to optimize the delivery of palliative care for cancer patients. *Ecancermedicalscience* 8: 492.
6. Afolabi OA, Nkhoma K, Maddocks M, Harding R (2021) what constitutes a palliative care need in people with serious illnesses across Africa? A mixed-methods systematic review of the concept and evidence. *Palliat Med* 35: 1052-70.
7. Jagwe J, Merriman A (2007) Uganda: Delivering Analgesia in Rural Africa: Opioid Availability and Nurse Prescribing. *Journal of Pain and Symptom Management* 33: 547-51.
8. Rhee JY, Garralda E, Namisango E, Luyirika E, Lima LD et al. (2018) An Analysis of Palliative Care Development in Africa: A Ranking Based on Region-Specific Macro indicators. *Journal of Pain and Symptom Management* 56: 230-8.
9. Worldwide Palliative Care Alliance. *Global Atlas of Palliative Care*, 2nd Ed 2020. London Worldwide Palliative Care Alliance 2020.
10. Pallipedia (2022) Brompton cocktail. <https://pallipedia.org/brompton-cocktail/>.
11. Merriman A (1989) *International Geriatric Medicine*.
12. Hanks GW, Hoskin PJ, Aherne GW, Turner P, Poulain P (1987) Explanation for potency of repeated oral doses of

morphine?. *Lancet* 2: 723-725.

13. Lötsch J, Weiss M, Ahne G, Kobal G, Geisslinger G (1999) Pharmacokinetic modeling of M6G formation after oral administration of morphine in healthy volunteers. *Anesthesiology* 90: 1026-38.
14. The Lancet (2022) Managing the opioid crisis in North America and beyond. *The Lancet* 399: 495.
15. Palliative Care Association of Uganda (2022) Status of palliative care in Uganda. <https://pcauganda.org/December>.

Copyright: ©2022 Dr. Anne Merriman. This is an open-access article distributed under the terms of the Creative Commons Attribution License, which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.