Support Visit to Guinea-Conakry

21-29 February 2016

Hospice Africa Uganda

International Programmes

29 February 2016

Executive Summary

A team from HAU International Programmes composed of **Dr Eddie Mwebesa, Sylvie Dive and Dr Francesca Elloway** went to Guinea Conakry from the 21st to the 29thof February 2016 to formulate impressions of the situation, train and support the infant national association SOPAG, do sensitisation and advocacy work with key stakeholders including the Ministry of Health, and encourage further development of palliative care in the country.

While the need for Palliative care in Guinea is great, there has been very little sensitisation and education so the country is almost naive to the specialty. Critical components outlined in the WHO public health approach for palliative Care are missing- essential pain medicines including affordable oral opioids, education, a conducive legal and policy framework and sub-optimal political will in a poor country recovering from the world's worst Ebola epidemic. Guinea's government allocates only a small budget to health and Palliative care is not a priority at this time. The Ministry of Health is yet to offer optimal support, and Palliative care is not yet well understood among doctors and health professionals who would be key allies.

SOPAG was formed in this environment and has persevered to operate against many odds. It is a national palliative care association but is set up in unique circumstances, and therefore is also operational- seeing patients and teaching.

SOPAG is an infant organisation which requires support- both financial and for organisational development in order to survive and become sustainable, but also in order to be the nucleus around which palliative care grows in Guinea and then spreads to the whole country.

Key recommendations are:

1. Marie Dounor Tonguino, the SOPAG President, writes an abstract and comes to APCA conference in August 2016, and thereafter has a placement at HAU where she will observe PC practice and visit partners in Uganda
2. The clinicians on the SOPAG team are supported to attend the Francophone PC Initiators Course. This will meet the crucial need for trained health professionals to offer quality PC to patients and also increase their competence and boost their confidence and credibility among other clinicians
3. That SOPAG further develop their capacity to teach. They require a Training of Trainers and those emerging from the Initiators course will offer leadership for teaching PC
4. SOPAG to increase their advocacy acumen and have a plan to systematically advocate for palliative care as the specialty is little known in Guinea.
5. Increase proportion/ number of clinicians on the SOPAG team in order to meet the projected increased workload, conduct home visits well, lead on technical aspects of patient care and increase visibility and engagement with other clinicians especially those in hospitals.
6. Following the meetings with the HAU IP team throughout the week and conference SOPAG systematically follows up all priority contacts made but also continues to identify new key contacts and cultivate relationships with them.
7. Complete the strategic plan for 1 year which SOPAG started during the day of the workshop and implement it through a work-plan.

8. SOPAG diversify their funding sources to reduce their vulnerability and increase their chances of sustainability. Consider applying for a grant from True Colours Trust which supports small-sized projects
9. SOPAG positions themselves well to be engaged by and involved in assessment of PC in Guinea which the Human Rights Watch intends to conduct
10. SOPAG to secure a presence in IGNACE DEN hospital, cultivate relations with their clinicians, and increase the number of patients they care for and the scope of their work.
11. Systematically develop and grow their relationship with the Ministry of Health through key contacts like Prof Toure and the officials met by the HAU IP team during the week.
12. It is imperative that regular reports are submitted to the MOH for accountability and as an update, and also to the NGO accrediting authorities
13. As there is no affordable oral morphine in Guinea it is crucial that SOPAG continues to advocate to the MOH and the Government so that this essential medication becomes available and accessible. Without this the practice of impeccable palliative care will not be possible.

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Acknowledgments

We would like to thank the Palliative Care Association of Guinea (SOPAG) for their kind invitation to Dr Anne Merriman and HAU IP to visit Guinea to support the young organisation and development and growth of Palliative Care in the country.

While she was unable to travel we are grateful to Dr Anne for her advice and insights into Palliative Care in Africa, and the approach to supporting Guinea, which was helpful to the IP team.

We cannot thank enough Hospice Africa France (Soins Palliatifs) for their invaluable work in fundraising, enabling the IP Francophone team to exist and carry out its activities.

We thank Camilla Borjesson through whom the vision for SOPAG was formed and who has been a constant supporter of Palliative Care in Guinea. We pray the seeds you planted grow and have much fruit.

We also thank Madame Diallo Fatoumata who is a pillar of strength, encouragement and support to her country-folk in SOPAG.

Prof Toure is a remarkable gentleman whose confidence in the SOPAG team has allowed them to grow and expand their activities. We thank you for being an ally.

Thank you to the staff of Hotel Rosak who were very hospitable and made our stay there comfortable; and to Henry and James who drove skilfully through Conakry's traffic jams twice a day until we completed our mission.

Lastly and specially we thank SOPAG for their vision and courage to start and persevere doing Palliative Care in Guinea with so little while giving so much. Our best wishes are with you, and we pray that through your efforts Palliative Care in Guinea will flourish.

List of Acronyms

APCA	African Palliative Care Association
CVW	Community Volunteer Workers
FCFA	Franc CFA / Common Currency of 14 countries in Western Africa
HAU-IP	HAU International Programmes
HAU	Hospice Africa Uganda
HA(SP)F	Hospice Africa France (Soins Palliatifs)
IC	(Palliative Care) Initiators' Course
IHPCA	Institute of Hospice and Palliative Care in Africa
MPU	Morphine Production Unit
NCD	Non-communicable Diseases
SOPAG	Palliative Care Association of Guinea
WHO	World Health Organisation

Introduction

Hospice Africa Uganda's International Programmes (HAU-IP) was invited to Guinea from 21-29 February 2016 to make an assessment of the situation of Palliative care in Guinea and support SOPAG- the Palliative Care Association of Guinea.

SOPAG is in its infancy as an organisation and is facing many challenges. It was against this background that HAU IP was contacted to make a mission to Guinea, make an assessment, do advocacy and sensitisation and make recommendations for ways forward.

The general aims and objectives of the visit were:

1. To meet with SOPAG and understand the circumstances under which they are operating
2. Explore what other organisations are involved in working with Palliative care patients
3. Contact and advocate for Palliative care at the Ministry of Health
4. Support sensitisation of the public and stakeholders about palliative care
5. Train SOPAG in areas required for their development as a team

After an overview of the country (Part 1), the report details the daily activities and achievements of the team, giving insight on the potential further development in palliative care (Part 2); finally the report gives recommendations to the team and some stakeholders encountered during their week (Part 3).

Part 1: Guinea and its Health System

Guinea- Key facts

Data come from UN data, the US Central Intelligence Agency, and Dr Aboubacar Conte- a Director at the Ministry of Health of Guinea

Ethnic groups: Fulani (Peul) 33.9%, Malinke 31.1%, Soussou 19.1%, Guerze 6%, Kissi 4.7%, Toma 2.6%, other/no answer 2.7% (2012 est.)

Languages: French (official) **note:** each ethnic group has its own language

Religions: Muslim 86.7%, Christian 8.9%, animist/other/none 7.8% (2012 est.)

Population: 11,780,162 (July 2015 est.)

Birth rate: 35.74 births/1,000 population (2015 est.)
Death rate: 9.46 deaths/1,000 population (2015 est.)

Age structure:

0-14 years: 41.87% (male 2,491,593/female 2,440,933)
15-24 years: 19.6% (male 1,165,462/female 1,143,022)
25-54 years: 30.46% (male 1,799,050/female 1,789,062)
55-64 years: 4.45% (male 250,531/female 273,756)
65 years and over: 3.62% (male 188,469/female 238,284) (2015 est.)

Life expectancy at birth:

total population: 60.08 years
male: 58.55 years
female: 61.66 years (2015 est.)

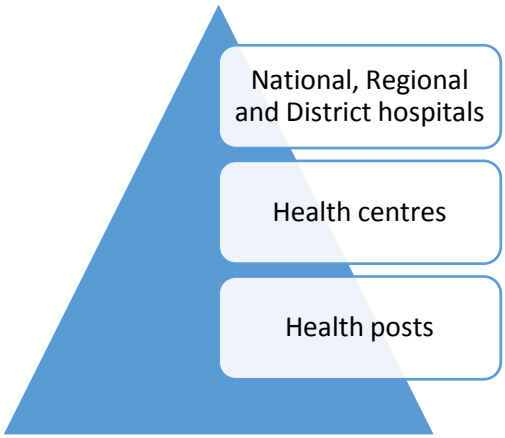
Currency:
West African Franc CFA: Common currency with Burkina Faso, Côte d'Ivoire, Guinea-Bissau, Mali, Niger, Senegal and Togo, within the West African Economic and Monetary Union. The West African Franc CFA is easily interchangeable with the Central African Franc CFA, official currency in Cameroun, Central African Republic, Congo Brazzaville, Gabon, Equatorial Guinea and Chad, member states of the Central African Economic and Monetary Union

The health system in Guinea

Health professionals' availability

For 1000 people	WHO recommendation	Guinea	Uganda
Nurses	2		1.3
Physicians	1	0.3	0.1

Organisation of Health care



Three levels of care arranged in a "pyramid":

- **Hospitals**
  - **National Hospitals: 3**
  - **Regional Hospitals: 7 spread over the different regions**
  - **District Hospitals: 26 with one in each district**
- **Health Centres**
  - **Improved Health Centres: more specialised and act as community health centres and where surgery is possible. 5 in Conakry and 3 outside**
  - **Health Centre: 417 in the administrative sub-districts**
- **Health posts: 988 spread all over the country.**

There are natural regions – costal, upper Guinea, lower Guinea, Forest Guinea. There is a vision for a hospital in each of the 4 regions and US$35 million has been found to build two of the hospitals. The health system has 3 principle functions: preventative which is the most cost effective, curative which is hospital based and rehabilitation. Although the Abuja declaration requires that at least 15% of the national budget is spent on health, Guinea spends only 3.5% on health. Of this proportion 60% goes to salaries of health workers, 15% administration costs and the rest actual care. The recent Ebola outbreak, which was the largest that the world has ever seen, has stretched the health system for over 2 years, and highlighted gross deficiencies in the health system.

Cancers

According to public statistics, the most common cancers are:

- **For women**: breast and cervix
- **For men**: prostate, liver, and colon
- **For children**: lymphomas and leukemias.

Radiotherapy: There is no radiotherapy facility in Guinea, patients need to go to Dakar, Senegal.

Chemotherapy is provided in the national hospitals, but there are no separate oncology departments.

The Cancer Plan

There is a National Cancer Registry held at the Anatomy and Pathology department of Donka hospital.

HIV/AIDS

- Adult prevalence rate : 1.55% (2014 est.)
- People living with HIV/AIDS: 118,000 (2014 est.)
- HIV/AIDS – deaths: 3,800 (2014 est.)

Major infectious diseases: **degree of risk:** very high

- **Food or waterborne diseases:** bacterial and protozoal diarrhea, hepatitis A, and typhoid fever
- **Vector-borne diseases:** malaria, dengue fever, and yellow fever
- **Water contact disease:** schistosomiasis
- **Aerosolized dust or soil contact disease:** Lassa fever
- **Animal contact disease:** rabies (2013)

Access and availability of morphine and opioid analgesics

Affordable oral morphine is not available. Injectable morphine is available in some national hospitals. The main analgesics are tramadol, paracetamol and the NSAIDs.

Need for Palliative Care

Based on the formula used by HAU:

- Number Living with HIV: 182,592(based on adult HIV prevalence)
- No. estimated to have AIDS (10%): 18,260
- No. of AIDS patients requiring PC (estimated 50%): 9,130
- Cancer needing PC (0.2% of pop): 23,560
- TOTAL requiring PC: **32,690**

Financing health care

Patients have to pay for health care out of their pockets.

Part 2: Daily activities and achievements

Day 1

1

Travel to Guinea

- The HAU-IP team travelled aboard ASKY from Senegal where they had spent a week on mission to support palliative care in Senegal. The team was met at airport by the entire SOPAG team and Camilla from Sweden and taken to Hotel Rosak, their residence.
- The residence was on the other side of town a long way from most of the activities planned for the week. The terrible traffic jam of Conakry meant that at least 3 hours were spent on travel daily

2

The team had a meeting with SOPAG to discuss plans for the week ahead.

Day 2

1

Meeting with SOPAG team in their office

- In 2013 the Mercy Ship, an organisation which has a naval vessel aboard which surgeries are conducted, visited Guinea and Camilla Borjesson, a palliative care nurse, was in charge of patients that required palliative care and Marie, the president of SOPAG, was her translator. Camilla and Marie were concerned about the follow up of the post-operative cancer patients when the mercy ship left and this resulted in the formation of SOPAG and the first seeds of palliative care in Guinea.
- There had been previous PC training of a doctor Valentin but he left soon thereafter to Cote d'Ivorie. Another Dr Mamoudou Conde , who was initially very keen and the first to invite HAU IP to Guinea, was trained on an Initiators Course in 2013 but is not working with SOPAG.
- The 7 current members of the SOPAG team were presented which include a doctor, a nurse, a finance officer, a secretary and a person responsible for media and publicity amongst others.
- The staffs are all volunteers receiving no salaries or payment; indeed voluntarily contribute money each month to the functioning of SOPAG. All the staff have other jobs out of necessity for incomes for daily living. They are clearly a very committed group which has been filtered out and have now normed over the course of several months.
- In 2014 they were able to get their organisation recognised by the authorities, and SOPAG is now registered as an association and their mandate is to promote access to palliative care for all and the objectives contributing to the improvement of the conditions of the lives of people with incurable illness; care and attend to the sick in palliative care; and to establish between the members the spirit of mutual assistance and active solidarity.
- SOPAG has no secure funding; Camilla is their main fund raiser from her contacts and home in Sweden and is very committed to helping them as much as she can. There is some support

from Madame Diallo Fatoumata, who is a French-Guinean now living in Conakry who understands the role of PC.

- They expressed their frustration at the fact that very few patients were referred to them and also the struggles that they have had with getting access to people at the Ministry of Health. Indeed they feel that their work is actively being blocked on occasions and doors are closed in front of them. Prof Toure has been instrumental in referring the first batch of patients to SOPAG.
- The HAU IP team noted that:
    - Palliative care is very new in Guinea and very few people know about it
    - SOPAG is a pioneer organisation and is in its infancy. While its members are committed it is vulnerable because all are volunteers and the organisation is not financially secure
    - SOPAG has comparatively few medical workers for the number of patients on its books. Currently there are only 2 patients.
    - The SOPAG office is housed in a building still under construction and is a small lock-up store with no windows. It gets hot during the day and as its just along the road very dusty.
    - Home visits were hindered by a lack of transport. Team members use motorcycles and taxis and as patients are far away this is a real challenge.
    - Camilla has given training of varying durations covering some technical aspects of Palliative Care.
    - There is a sense of frustration among the SOPAG members that the government is not yet taking Palliative care as a priority and has not embraced SOPAG despite their previous attempts to reach out
    - SOPAG intended to utilise the eminence of the HAU IP team to advance the palliative care agenda in Guinea

The SOPAG team at their office

2 Visit to Ministry of Health

- A meeting with the Minister of Health had been planned and invitations for this hand delivered 2 months in advance. On the day of the meeting it was discovered that none of the 3 letters had been delivered to the Minister and he was away. Attempts to meet with any official with delegated authority were initially futile. The SOPAG team insisted on using all protocol to meet with any official willing to meet with the PC team

- The team met with Dr Mamady Kourouma, the Director of Family Health and Nutrition. The great need for PC in Guinea was highlighted and the need for collaboration between several stakeholders including the Ministry of Health for Palliative care to become integrated in the health care system.
- He explained that his directorate was not directly concerned with the matter of Palliative care and he shared with us the contacts of Dr Sandouno with whom we later scheduled a meeting.

The HAU IP and SOPAG team meeting with Dr Mamady Kourouma at the MOH

Day 3

1

Visit to IGNACE DEN Hospital

- Ignace Den is one of the 3 national hospitals, one of which is currently closed for renovation. It has 45O beds and multiple specialties, including paediatrics, cardiology, radiology, rheumatology, internal medicine, surgery. There is no separate oncology speciality and no palliative care team.
- The Director Dr Mohamed Awada, explained that some doctors offer some pain relief to their patients and they use injectable morphine within the hospital. There is no oral morphine in the hospital.
- Ignace Den is a teaching hospital and nurses and doctors come to do placement there.
- SOPAG organised for a grand round to be held and this was attended by the hospital director and Dr A Ketty, a rheumatologist who chaired the grand round and was identified as the palliative care focal person for the hospital, a responsibility that he accepted.
- SOPAG presented one of their current home care patients as a case study. This was followed by a discussion of the case by 45 medical personnel, some of which were medical students.
- The principle topics of discussion included truth telling and confidentiality, religious issues, and pain management.
- The audience requested to see a photo of the patient which had not been prepared and there was concern amongst the SOPAG team that without a photo the audience were not convinced that this was a real patient.

- There was a vibrant discussion around whether or not to disclose diagnosis to patients and the process of breaking bad news and sharing information with the family care givers.
- Part of the grand round was covered by the media, who also interviewed the director and it is hoped that this publicity will increase the public's understanding of palliative care.
- The director gave the IP team a tour of the hospital.

Media interview of HAU IP, SOPAG and IGNACE DEN Hospital director Dr Awada

2 Meeting with Professor Toure Aboubacar

- Prof Toure is a senior surgeon and lecturer at the University. His involvement with palliative care started after he was approached by SOPAG and accepted to refer patients for palliative care to them and has so far referred 8 patients over a 2 year period.
- The team discussed the importance of collaboration between hospital clinicians and the palliative care team. The SOPAG team had highlighted the challenge of clinicians not understanding the role of palliative care and the SOPAG team. As clinicians are gatekeepers to hospital based patients, the IP team reiterated the crucial link between pro-palliative care physicians like Professor Toure and the palliative care service.
- Prof Toure pledged to continue supporting palliative care and referring patients as needed to the SOPAG team.
- Prof Toure was instrumental in securing a meeting with Dr Conte at the Ministry of Health, which happened the next day.

Presenting the Blue Book to Prof Toure, a key ally of the SOPAG team

Day 4

1

Meeting at Ministry of Health with Director of Hospital Care, Dr Aboubacar Conte

- The team together with the SOPAG team, were given details of the health structure in Guinea, highlighted in part 2 above.
- The director appreciated the huge need for palliative care presented by the HAU-IP team
- He highlighted how much the health structure is stretched and the impact of the Ebola epidemic.
- Palliative care is clearly not high on the priority list of the government. There is emphasis on infrastructure development, building hospitals, importing equipment, and stocking labs. The director initially understood that palliative care required a lot of technology and needs firm diagnoses before it can be undertaken. He stated that the government was in the process of relooking at the health system.
- The team shared with the director the desire of Human Rights Watch to conduct a comprehensive situational analysis and the request for co-operation and partnership with the Ministry for this to be successfully undertaken. A protocol by HRW was requiring urgent information for timely submission of a grant.
- The team also explained recent advances in palliative care landscape of Guinea, including the formation of a national association of palliative care SOPAG.
- The Director pledged to support efforts in palliative care

Meeting with Dr A. Conte of the Ministry of Health

2 Meeting at Ministry of Health with Dr Sabouna

- In addition to his role in the MOH, Dr Sabouna is also a senior teaching faculty member at the University Medical School and has strong links and influence with the Ministry of Education.
- The team explained the essence of the meeting with Dr Conte.
- The vital importance of including palliative care in the medical and nursing curricula was discussed and agreed upon in principle.

3 Meeting at Des Ecoles Privees de Sante

- This is a private nursing school, indeed the first private one in the country.
- The school trains lab technicians, midwives, public health technicians and nurses. At the time of the visit only the first year students were in class, the two other years were doing field work.
- The team met with several members of staff including the Director and teaching faculty.
- The need for palliative care in Guinea was highlighted and also the centrality of educating nursing and medical students in order for professionals to graduate with palliative care knowledge and competencies. The possibility of continuing medical education was also raised.
- The director highlighted that the nursing school has many challenges including lack of teaching aids and lab materials. Also 90% of graduates cannot be absorbed by the civil service so have to find work in the private sector.
- The main challenge of the curriculum is that it is decided by a West African body and the same curriculum is used in several countries after being ratified by the Ministry of Education. Inclusion of palliative care at a single nursing school would be difficult and the director advised that discussion for inclusion/expansion of palliative care have to be done at a ministerial level. Also both the ministry of health and the ministry of education are involved with nursing and medical curricula
- HAU IP team agreed to share a copy of the palliative care curriculum used in Uganda and also informed the Director that HAU IP team had initiated discussion with the MOH regarding palliative care education.
- The Director was keen for his school to be the pioneer for teaching palliative care.

4 Sensitisation of first year Nursing Students of Des Ecoles Privees de Sante

- The HAU IP team gave two short interactive lectures, the first an introduction to palliative care followed by one concerning the role of nurses in palliative care. This was attended by students and faculty members as well as the SOPAG team.

- Although the 50 students were only at the beginning of their training as nurses they were very engaged with the subject and contributed well in particular concerning the importance of holistic care. They seemed to appreciate the importance of spending time with palliative care patients and understood that their role would not be exclusively concerned with medical aspects of care.
- The IP team highlighted the huge palliative care need in Africa, the scarcity of doctors and the importance of nurses who are at the forefront of care and upon whom the responsibility for most palliative care lies.
- The team encouraged the students to remember the basic essential of palliative care, and when they are on their next placement to actively look for a palliative care patient and spend some time with them.
- The director showed us around the school at the end of the session with the students.

Teaching first year nursing students at their school

Day 5

1

Meeting with teaching faculty at Gamal Abdul Nasser University (GANU)

- GANU started 1967 and is the largest and only public University teaching medical students in the country. There are 2 other private medical schools
- Teaching faculty is from the Ministry of Health, Ministry of Education and hospital directors. There are 4,125 students in 4 departments all of which are undergraduate courses. 10% are foreign students and many graduates work in other neighbouring countries.
- Currently there are 50 medical students, 30 dental students and 75 pharmacy students. Medical student enrolments have been progressively reducing from 250 in 2014 to 150 in2015 due to the Ebola epidemic and shortage of places for student placement in hospitals.
- The dean appreciated the agenda of the HAU IP team coming to advocate for palliative care education which is a key component according to the WHO public health model for palliative care.
- The dean expressed that there is increasing demand for palliative care and thus the need for both clinical services but also education.

- The dean explained that palliative care isn't taught in the preclinical years but aspects are taught during the later years. The vision is for palliative care to be in the programme for 5th and 6th year medical students. He requested support from HAU for inclusion of palliative care in the curriculum and pledged to work closely with SOPAG.
- The programme for a teaching session for 3rd year medical students who were the only ones available was agreed and the team presented a copy of the blue book to the dean.

Meeting with the Dean of Gamal Abdul Nasser University

2 Palliative care teaching for medical students

- Although the team has prepared to teach 50 students and use a case based study approach, they were pleasantly surprised with an opportunity to sensitise over 500 students!
- An introduction to palliative care was presented followed by a presentation of an actual palliative care patient being looked after by SOPAG. After each presentation there were many questions posed by the students, particularly focusing on spiritual care, euthanasia, and psychological assessment.
- Although work was initially planned in small groups with the intention of discussion the overwhelming number of students made this impractical. After a satisfactory recap by students of salient points about palliative care it was agreed that they would form small groups after the session to discuss the different questions. The questions were designed around making a problem list and giving practical solutions, ethical issues, and the breaking of bad news.

Teaching 500 medical students at Gamal Abdul Nasser University

3 Meeting of HAU IP team with Camilla Borjesson

- Camilla is a palliative care nurse who worked on the Mercy Ship and approached by Marie to support the formation of a palliative care organisation to care for post operative patients. She is in effect the founder of SOPAG and has been supporting them from her home in Sweden for the last 2 years.
- Camilla is very concerned for the future of SOPAG
- She explained that the current team understand the need for medical personnel but are anxious that if training is focused on medical personnel their roles may be diminished as well as their status within SOPAG
- We discussed the possibility of Marie, the SOPAG president and co-founder, coming to HAU for a placement experience and to strengthen her leadership skills. The nurse could join the Francophone initiators course.
- We also discussed the situation with the current nurse and doctor. The doctor we understand is in the process of finishing his studies, and is new with SOPAG. They both have paid jobs. Both were however observed to be more reserved. The HAU IP team were unsure of their acumen for leadership and public relations.
- We discussed the proposed situational analysis study that Human Rights Watch hope to do in Guinea, and the importance of SOPAG being involved in that, maybe doing the data collection to increase their visibility and status with the stakeholders.
- Important discussions were had around strategic matters including:
    - The need for clarity on SOPAG's vision, mission and objectives
    - The need for a strategic plan to direct their work plan for the short and intermediate term
    - The need for measurable and realistic targets
    - The advantages that clinical trained team members would bring to SOPAG
    - The need for securing funding for SOPAG beyond Camilla and her contacts
    - The clarification of the roles of the founder, Camilla, and the transition to greater autonomy. The pressure for the organisation to be independent, secure and sustainable is weighing on Camilla.
    - Attention to legal and procedural requirements of this organisation in Guinea
    - Attention to the development of robust governance structures which will promote confidence with government, hospitals and donors.

- The merits of office or space for SOPAG within a hospital to increase their presence and visibility

- The team assesses that the two greatest needs for SOPAG at this stage of the organisation's growth are leadership and trained medical personnel within their team.
- The above matters require consideration by the HAU foundation or HA France through the International programmes department and APCA.

Day 6

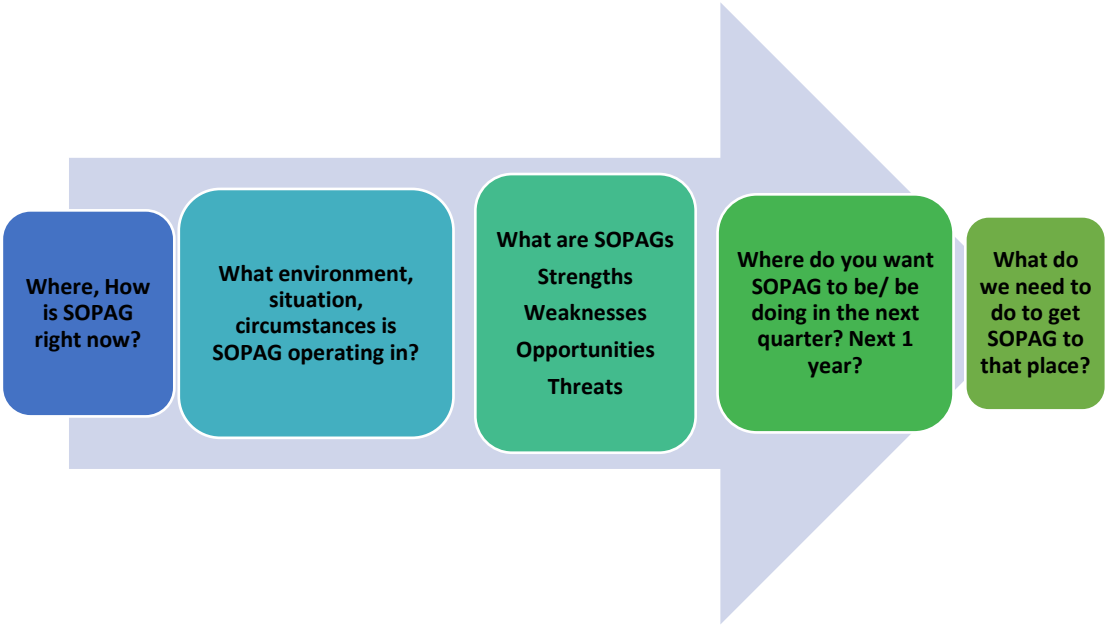
1 Workshop for SOPAG

The SOPAG team had identified that they require training and included this within the week's schedule. The content of teaching was discussed over the previous days and refined on the day of the training. A workshop style of teaching was best suited for the team. It considered that the team was made up of adult learners who would direct their own learning. The IP team agreed ground rules for the day and emphasised that the workshop would be a safe space for sharing and learning. This training aimed to build onto what Camilla had commenced.

- The SOPAG team expected to cover over the course of the day teaching and training on:
  - Technical aspects of PC
  - How to work as a team
  - How to advocate to authorities; Effective advocacy and message delivery
  - How to establish and manage projects
  - How to prepare SOPAG for expansion and the future- Strategic discussions
  - Effective team management
  - Effective info and communication management system
  - Effective visits to our patients
  - Effective organisational meetings
  - Fundraising and its management
  - Report writing and interpretation
  - Plans for action and implementation
  - Ethos- Respecting and caring for one another as a team; Team dynamics
  - Knowledge to train others- Training of Trainers
  - How to maintain and manage contacts SOPAG has made
  - To embed PC within the teaching of university students
  - Role definition and support to be effective in their different roles

Strategic thinking and planning was identified as a critical area and the bulk of the day was spent on this.

- The framework used by the SOPAG team to start their process of strategic thinking for the next 1 year is represented below:



- A summary of each of these areas as suggested by SOPAG is given below:

Where and how is SOPAG right now?

SOPAG is a small organisation, in its beginning stage with few members and few patients. Its work is focused on home visits. It has an office as its headquarters in Conakry which is too small to allow them to operate as they would like. They have a clear idea of what they want to do but are lacking in funds to do all the work they would like to do. They are a volunteer organisation that operates with little technical knowledge in terms of personnel. The organisation is not well known.

What environment, situation and circumstances is SOPAG operating in?

The current environment SOPAG is operating in is one where there is poor understanding of what palliative care is and the hospital doctors are still resistant to palliative care. The MOH is yet to develop stronger relations with SOPAG and be more supportive of palliative care. The political environment is unstable and economically corruption is a huge problem and although the country is rich, the people are poor. The health sector receives only 3.5% of the national budget. There are ethnic barriers to palliative care and traditional beliefs can also be a problem. SOPAG has a challenge with transport, they do not have their own transport, the traffic in town is very heavy and some patients live quite a long way away. There can be political instability with strikes. The fact that all the staff of SOPAG are voluntary means that they need to have another job to provide them with money. Palliative care is not well known amongst medical personnel or amongst the population in general.

SWOT Analysis of SOPAG:

Strengths:

- Pioneer organisation
- Patients are appreciative of SOPAGs care of them
- The staff are united, passionate, have perseverance and are very willing
- The staff all pay a monthly contribution to SOPAG
- New contacts have been made and the media has made SOPAG better known

Weaknesses:

- The staff are all part-time as they need paid jobs
- SOPAG doesn't have an organogram
- The staff do not have a lot of knowledge on how to manage an organisation
- They have little knowledge about advocacy
- They have limited office space
- They are unable to use morphine, so an essential aspect of patient care is not met
- They do not always have the time and the means to do what they want
- They lack transport
- They have few medical people in their team

Opportunities:

- They are the first to start palliative care in the country, so have an historical advantage
- There is plenty of work to do with many cancer patients
- There are opportunities to expand their work to other areas of Guinea
- The team members are mostly bi-lingual speaking English and French
- Prof Toure is there to give SOPAG both patients and support
- They have cared for 12 patients over the last 2 years
- Madame Diallo and Camilla are available to give financial and moral support
- HAU has been contacted and following the delegation's week in the country, organisational support could follow
- There is also the opportunity for abstract submission and attendance at the APCA conference in August. If a SOPAG team member came to the conference he/she could spend some time at HAU and her partners
- Human Rights Watch is intending to carry out a comprehensive assessment of palliative care in Guinea. SOPAG has expressed interest in being involved with the data collection.
- Possibilities of collaboration with Ignace Den hospital

Threats:

- Financial insecurity of the organisation
- Political uncertainty
- Team has few medical personnel
- The lack of interest and support for palliative care by hospital clinicians and the MOH and this could to a delay in palliative care being accepted and taking root in Guinea
- Fear of sabotage of palliative care by authorities who don't understand it or think that there is financial loss that would come from the success of palliative care

Plans for the next year were commenced but due to time factors was exhaustively completed:

- Spread palliative care to neighbouring towns
- Train 15 community volunteers in these towns
- Find more suitable office space
- Formulate an understanding with Prof Toure-proposing at least 1 new patient each week
- Write an abstract for the APCA conference and apply for bursaries to travel to Uganda
- Work with HRW on the assessment for Palliative care for Guinea if this opportunity arises

- Request for space or a room at Ignace Den Hospital for increased palliative care presence there
- Meet every quarter to discuss quarterly plans and continue their weekly planning meetings
- Write follow-up letters to all new contacts the week of HAU IP teams visit.

Training with the SOPAG team

- Due to time constraints and fatigue after a long hot day of training the team agreed that following aspects would form further training and discussion at their weekly meetings:
    - Effective meetings
    - Effective advocacy
    - Completion of strategic plans for the next year
    - Plans to continue teaching sessions/grand rounds at Ignace Den Hospital

Day 7

1 Conference organised by SOPAG

The theme of the conference was “Sensitisation of Palliative Care for Guinea” and was held at John Paul II Hospital and was attended of total of 35 participants.

- The SOPAG president Marie welcomed delegates who included representatives from the MOH, Universities and Nursing School.
- She highlighted the need of palliative care which is increasing
- She gave a history of the start of palliative care and SOPAG and a summary of how they operate.
- The purpose of the organisation is to promote access to palliative care for all and the objectives contributing to the improvement of the conditions of the lives of people with incurable illness; care and attend to the sick in palliative care; and to establish between the members the spirit of mutual assistance and active solidarity.

- Successes of SOPAG include training on several occasions by expatriates from Mercy Ships and from different countries including USA, UK, and Sweden; continuation of visits to patients in their homes; and offering social materials to patients.
- The contributions of Camilla Borjesson, Emma O'Reilly and Madame Diallo Fatoumata were all acknowledged and applauded. SOPAG's main challenges were stated to be: inconsistent number of patients; limited funds for planned activities; difficulties relating with hospital medical professionals; and misunderstanding of palliative care which is hindering relations with authorities and partners.
- Marie appealed for the government, partner institutions, and well-wishers to give their support to SOPAG for the continuation of the activities and growth of palliative care in Guinea.

Dr Eddie Mwebesa gave a keynote address on behalf of Dr Anne Merriman whose apology was delivered to the conference. The following were highlights of the keynote address:

- The title was "Why Palliative Care in Africa and in Guinea?" and talk covered the history of PC starting with Fabiola, through the contribution of Dame Cicely Saunders and spread to the world and Africa.
- Palliative Care was defined, its components outlined and the meaning of holistic care delineated
- The historical place of HAU was shared including its vision, mission, objectives and its international work.
- The success of PC in Uganda as a country and the contributing factors were shared.
- The central role of essential pain medications and affordable oral morphine was emphasised. This included the process of its manufacture over a "kitchen sink".
- The essence of the ethos of Hospices in Africa was shared.
- There was a vibrant discussion on what compassion is and how it is crucial for PC to move forward in Guinea which has over 45,000 in need of Palliative Care
- A summary of what the 2014 World Health Assembly required signatory nations to achieve was given. PC needs to be integrated into the health care system of Guinea at all levels and essential pain medications including opioids made universally available.
- The pioneering work of SOPAG and its founders was acknowledged and Dr Eddie appealed for support for PC from all participants and the organisations they were representing.
- 3 Blue books were given to clinicians who stated that they were directly involved in patient care and 2 Blue books were given to SOPAG.

Camilla Borjesson spoke about the history of SOPAG after her and Marie's involvement on the Mercy Ship. She was complementary of SOPAG and also pledged to continue supporting the organisation.

Madame Diallo Fatoumata also addressed the conference.

- She is a Guinean who has spent 35 years in France and is involved in a lot of charity work.
- She's the president of at least 2 not for profit NGOs which are involved in the education of underprivileged children in Guinea.
- She has consistently provided support for the medications of patients that SOPAG looks after
- She attested at the conference that SOPAG is a bona fide organisation and they care for actual patients and she has been with them on home visits.
- She pledged to continue supporting the work of SOPAG.

There was some discussion held after the above addresses as below:

- The conference attendees expressed a need for training in palliative care, but it should be in country to safe costs.
- Prof Moussa Koulibaly, who is in charge of the National Cancer Registry, advocated for palliative care training to be linked with cancer care. He also appreciated the sensitisation conference but decried the low attendance and advocated that also social workers and people who are involved with care outside hospital be trained
- The conference learnt about collaboration of GIZ, a German international development agency, and Gamal Abdul Nasser University for developing and training medical students. This is a collaboration that could be contacted to start a training of trainers for palliative care for final year medical students.
- Dr. Diallo Taibou, an anaesthetist, noted that SOPAG is not widely known. She expressed much interest in palliative care. She noted that affordable oral morphine is not available for the treatment of pain and only injectable morphine is present in Guinea. The IP team interested her in joining the francophone initiators course and supporting palliative care.
- There was a lot of interest about SOPAG and its activities and the conference was a good opportunity to network and partner.
- The role of the National Palliative Care Association and its relationship with doctors, hospitals, the MOH and other care organisations was discussed. The IP team shared their experiences from Uganda and other African countries.

Key note address by Dr Eddie at the conference

- SOPAG team gave tokens of appreciation to the co-founder Camilla, to the HAU IP team and to Dr Anne.
- The IP team prepared and gave to the SOPAG team on a flash disk a folder containing all the resources and presentations made during the week and key electronic documents concerning palliative care.

The SOPAG team after the conference. At the back in the middle is SOPAG co-founder Camilla

- The conference marked the closure of the IP team's work in Guinea.

Part 3: Palliative Care in Guinea

The SWOT Analysis

1 The Strengths in Guinea

1. There is a national association SOPAG which has very committed members
2. Camilla Borjesson who was instrumental in starting SOPAG has remained available and actively engaged. She still mobilises funds for SOPAG and is working towards the organisation's sustainability
3. The SOPAG team is committed and shows perseverance in the face of challenges
4. Awareness about palliative care is increasing and the activities of the week were planned to increase sensitisation and bring on board new partnerships
5. Madame Diallo Fatoumata is a great supporter and advocator for palliative care and has pledge continued support

2 The Weaknesses in Guinea

1. None of the medical and nursing schools in Guinea has palliative care within their curricula
2. There are no health professionals trained in PC. The 2 persons trained in the past are no longer actively involved with Palliative care in the country
3. Guinea is a country of low resource, and has been stretched by the Ebola epidemic. The budget for health is small and Palliative care is not a priority
4. The staff are all part-time as they need paid jobs and there is need for a permanent presence in the SOPAG office. This should be someone who is skilled in organisation management
5. Affordable oral morphine is not available in the country and this is a major limitation for the practice of palliative care in Guinea as pain can't be controlled.
6. The SOPAG team has few medical people and this is a challenge during interfacing with hospital clinicians and the MOH.

3 The Opportunities

1. The Human Rights Watch has expressed desire to work collaboratively with the MOH and the government to conduct a comprehensive situational analysis. This will generate robust information on the need for PC in Guinea and be a tool to advocate for much needed progress
2. Several contacts were made during the week for SOPAG to follow up on.
3. Prof Toure is a key ally for SOPAG, both for patient care and support

4. Possibilities of collaboration with Ignace Den hospital and increased presence, work and visibility in this national hospital
5. Madame Diallo and Camilla are available to give financial and moral support
6. There is also the opportunity for abstract submission and attendance at the APCA conference in August. If a SOPAG team member came to the conference he/she could spend some time at HAU and her partners

The Threats

1. The Ministry of Health has not demonstrated much enthusiasm when they have been approached and Palliative Care is not high on the list of the government's priorities
2. The comparatively low numbers of clinical staff on the SOPAG team makes them vulnerable by not being taken seriously by hospital clinicians and the Ministry of Health
3. SOPAG and Palliative Care in Guinea has no secure funding and is run and managed by volunteers. This is a vulnerable position and there is risk of loss of committed persons from the cause of Palliative care
4. Fear of sabotage of palliative care by authorities who don't understand it or think that there is financial loss that would come from the success of palliative care

Our recommendations

1. Marie Dounor Tonguino, the SOPAG President, writes an abstract and comes to APCA conference in August 2016, and thereafter has a placement at HAU where she will observe PC practice and visit partners in Uganda
2. The clinicians on the SOPAG team are supported to attend the Francophone PC Initiators Course. This will meet the crucial need for trained health professionals to offer quality PC to patients and also increase their competence and boost their confidence and credibility among other clinicians
3. SOPAG further develops their capacity to teach. They require a Training of Trainers and those emerging from the Initiators course will offer leadership for teaching PC
4. SOPAG to increase their advocacy acumen and have a plan to systematically advocate for palliative care as the specialty is little known in Guinea.
5. Increase proportion/ number of clinicians on the SOPAG team in order to meet the projected increased workload, conduct home visits well, lead on technical aspects of patient care and increase visibility and engagement with other clinicians especially those in hospitals.
6. Following the meetings with the HAU IP team throughout the week and conference SOPAG systematically follows up all priority contacts made but also continue to identify new key contacts and cultivate relationships with them.
7. Complete the strategic plan for 1 year which SOPAG started during the day of the workshop and implement it through a work-plan
8. SOPAG diversify their funding sources to reduce their vulnerability and increase their chances of sustainability. Consider applying for a grant from True Colours Trust which supports small-sized projects

9. SOPAG positions themselves well to be engaged by and involved in assessment of PC in Guinea which the Human Rights Watch intends to conduct
10. SOPAG to secure a presence in IGNACE DEN hospital, cultivate relations with their clinicians, and increase the number of patients they care for and the scope of their work.
11. Systematically develop and grow the relationship of the Ministry of Health through key contacts like Prof Toure and the officials met by the HAU IP team during the week.
12. It is imperative that regular reports are submitted to the MOH for accountability and as an update, and also to the NGO accrediting authorities
13. As there is no affordable oral morphine in Guinea it is crucial that SOPAG continues to advocate to the MOH and the Government so that this essential medication becomes available and accessible. Without this the practice of impeccable palliative care will not be possible.
14. A committed Guinean (preferably a doctor) to advocate for SOPAG and Palliative Care and then a Nurse leader to continue the work. This can be after a PC professional from outside Guinea supports the team for a year or two.

Conclusion

As there has been very little sensitisation and education Guinea is a country which is almost naive to palliative care. Critical components outlined in the WHO public health approach for palliative Care are missing- essential pain medicines, education, a conducive legal and policy framework and sub-optimal political will in a poor country recovering from the world's worst Ebola epidemic. Guinea's government allocates only a small budget to health and Palliative care is not a priority at this time. The Ministry of Health is yet to offer optimal support, and Palliative care is not yet well understood among doctors and health professionals who would be key allies.

SOPAG was formed in this environment and has persevered to operate against many odds. It is a national palliative care association but is set up in unique circumstances, and therefore is also operational- seeing patients and teaching.

SOPAG is an infant organisation which requires support- both financial and for organisational development in order to survive and become sustainable, but also in order to be the nucleus around which palliative care grows in Guinea and then spreads to the whole country.

Appendices

Appendix 1: Key contacts for Guinea

Names	Contact details	Position
Camilla Börjesson	camilla.borjesson71@gmail.com	PC Nurse from Sweden and co-founder of SOPAG
Dr. Mamady Kourouma	mamadykourouma@yahoo.fr +224664395897 +224622938532	National Director of family health& nutrition, (MOH)
Dr. Aissatou Diallo	Diassat2005@yahoo.fr +224664382728/6225556945	Deputy to Dr. Mamady Kourouma (in MOH)
Dr.Ketty Camara	akettycamara@gmail.com/ +224622012684/657311986	Head of rheumatology in Ignace Deen National Hosp
Dr. Mohamed Awada	622401237	Director of Ignace Deen National Hosp
Tamba Dah Sandouno	Sandounodahz@yahoo.fr 628969856	General secretary of SOPAG
Pr. Toure Aboubacar	dratuchi60@gmail.com	Surgeon& teacher in university and hosp Ignace Deen
Dr. Sandouno Sah Dimio	ssahadimio@gmail.com	Division of health and care(MOH)
Dr. Aboubacar Conte	+224657297472/621297472 Bocar49@yahoo.com, aboubacarconte149@gmail.com	National Director of Hospitals and care(MOH)
Dr.Abdomahmane	abdomihmantoulde@yahoo.fr 628436447/669436447	Founder of nursing school (le sauveur)
Dr. Diallo Oumar Sadio	docteursadiallo@yahoo.fr	Teacher of pharmacology in nursing school
Pr.Mamadou Bobo Diallo	profbobodiallo@gmail.com +224655760448	Dean of medical school/ Gamal Abdul Nasser university
Dr. N'faly Camara	628581508	General Secretary of Gamal Abdul Nasser university medical school
Diederik Lohman	lohmand@hrw.org	Human Right Watch desire to conduct comprehensive situational analysis of Guinea
Diallo Taibou	dtaibou73@gmail.com/ 622123006	Anesthesiste technician in Ignace Deen Hospital
Prof. Moussa Koulibaly	mtoty09@gmail.com/ 628333061	Director of Cancer registry Ignace Deen Hosp
Dr . Martin Cisse	cmguinean@.fr/622609303	Internal Medicine Ignace Deen Hosp
Dr. Toure Moustapha	touremohamedm@gmail.com/664972535	Gamal Abdul Nasser hospital Faculte de Medicine Pharmacie et Odontostomatologie(FMPOS)
Madame Diallo Fatoumata	666471269	President of Assistant Sociale ONGO which provides medicine for poor children in Guinea