ACCELERATING PALLIATIVE CARE DEVELOPMENT IN WEST AFRICA INTEREST GROUP MEETING

HELD ON TUESDAY 16TH AUGUST 2016

AT THE

5TH INTERNATIONAL AFRICAN PALLIATIVE CARE CONFERENCE

SPEKE RESORT, MUNYONYO, KAMPALA UGANDA

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1) INTRODUCTION

The World Health Organization defines palliative care as an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness.[1] It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual. Palliative care is explicitly recognised as a human right, under the International Human Right to Health from the International Covenant on Economic, Social and Cultural Rights (ICESCR) Article 12.1 (1996).[2]

Each year an estimated 40 million people are in need of palliative care, 78% of whom live in low- and middle-income countries. For children, 98% of those needing palliative care live in low- and middle-income countries with almost half of them living in Africa. WHO (2015) reports that only 14% of people who need palliative care worldwide currently receive it. By 2014, 32% of the world's countries had no identified hospice and palliative care services.

In May 2014, the World Health Assembly passed a resolution on strengthening palliative care as a component of comprehensive care throughout the life course. The resolution, which is a manifestation of the right to quality care for adults and children with life limiting illnesses, outlines responsibilities of WHO member states. These are based on nine key areas: evidence based palliative care policies; funding and allocation of human resources; basic support to all care givers including families, volunteers and others; education and training at all levels; assessing basic palliative care needs including pain medication requirements; revision of national and local legislation and policies for controlled medicines to improve access; updating national essential medicines lists; fostering partnerships; and implementing and monitoring palliative care actions in the included in WHO's global action plan for the prevention and control of NCDs 2013–2020.

i. Background

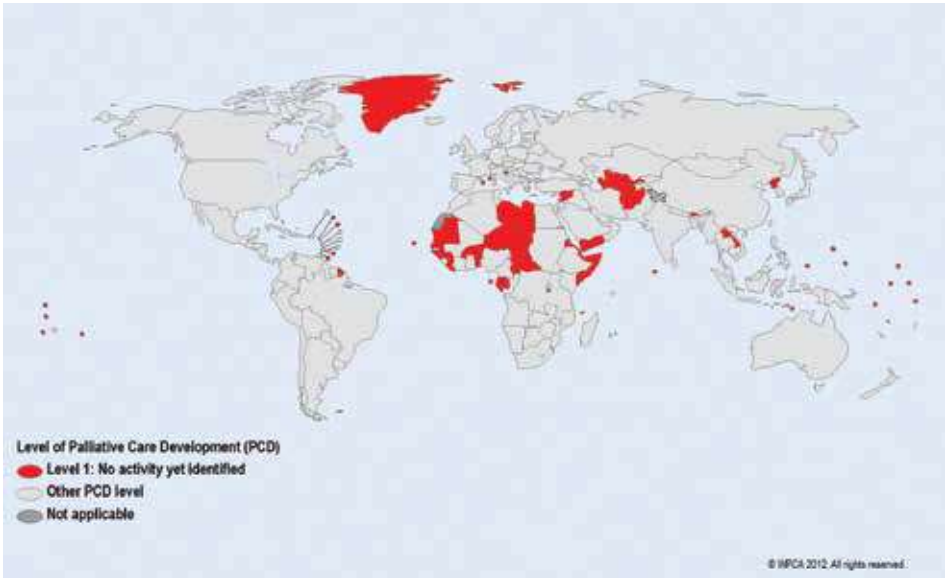
In Africa, health systems have remained over stretched with an increasing and perturbing disease burden, great geographical distances and late presentation of illness, all of which contribute to the extensive need for palliative care. Even with significant investments in prevention and treatment services for diseases such as HIV and non-communicable diseases (NCDs), people will continue to fall ill and die from AIDS, NCDs and Neglected Tropical Diseases, and many of these will require palliative care. The global, regional and national need for palliative care will continue growing owing to the rising burden of non-communicable diseases (NCDs) and ageing populations.

While remarkable palliative care interventions have been undertaken in Eastern and Southern Africa, especially in the Anglophone countries, there is still a lot to be done for the West African

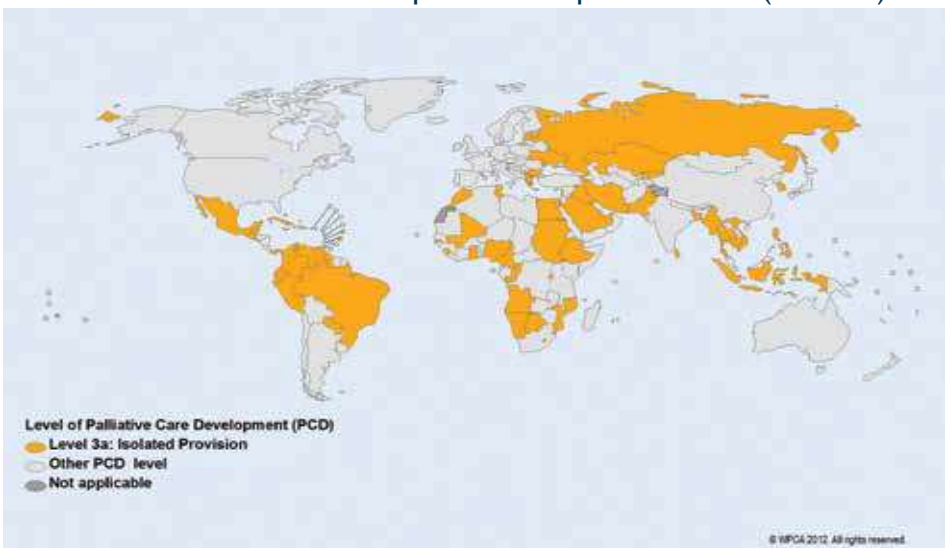
[1] World Health Organization. Fact sheet No. 402, July 2015. http://www.who.int/mediacentre/factsheets/fs402/en/
[2] United Nations Human Rights. International Covenant on Economic, Social and Cultural Rights, December 1966. [Online]. Available at: http://www.ohchr.org/EN/ProfessionalInterest/Pages/CESCR.aspx [Accessed: July 2015].

and Francophone countries. Countries in West Africa have had very limited or no known palliative care interventions. Integration of palliative care in policy, education, health service delivery as well as availability of palliative care medicines and technology are very limited in this region. The few palliative care capacity building and awareness raising activities in West Africa have been isolated interventions. Below are maps extracted from the Global Atlas on palliative care showing the status/levels of palliative care in the world. It is observed that most West African countries either do not have known palliative care activities or have isolated provision of palliative care.

Countries with no known hospice-palliative care activity (Level 1)



Countries with isolated provision of palliative care (Level 3a)



Source of maps (Global Atlas of Palliative Care at the End of Life).

APCA exists to ensure availability of palliative care for all in Africa and is therefore conscious of the palliative care service provision gap that exists in West Africa. As an effort to facilitate palliative care stakeholders from West Africa to identify the palliative care gaps/needs in the region and develop appropriate strategies, APCA organized the Accelerating Palliative Care development in West Africa, an interest group meeting for West African countries at the 5th triennial APCA conference.

2) THE MEETING

The meeting was held on **Tuesday, 16th August 2016** at **Speke Resort Munyonyo**, **Kampala Uganda** and was attended by a total of 38 participants from 14 countries including; Cameroon, Nigeria, The Gambia, Cote d' Ivoire, Senegal, Ghana, Togo, Sierra Leone, DRC, Uganda, Burundi, Kenya, Malawi and France.

The meeting was co-chaired by 2 senior palliative care people from West Africa namely; Dr Jonah Wefuan a Specialist Internist & Rheumatologist, Consultant Physician CEO/Director, Greenfield Dynamic Medical Centre Cameroon and former Chairman APCA Board of Directors and Prof. Olaitan Soyannwo FAS, a Consultant Anesthesiologist, Pain and Palliative care, UCH, Ibadan. Director Centre for Palliative Care, Nigeria and former Member of APCA Board of Directors.

i. Aim of the special interest group meeting

To facilitate dialogue amongst palliative care stakeholders from West Africa on the status of palliative care in the West African region and develop the most appropriate and practical strategies to ensure that palliative care for all is achieved in the region.

ii. Objectives of the workshop

a. To identify and prioritize the major palliative care needs and gaps for West Africa.

b. Discuss and adopt the strategies to effectively address the palliative care needs for West African countries.

c. To identify funding and other opportunities that can support the integration of palliative care within the health systems in West African countries.

iii. Participants and attendance

Of the 14 countries that were represented at the meeting, 8 were from West Africa (both Anglo and Francophone). These included; **Cameroon, Nigeria, The Gambia, Cote d' Ivoire, Senegal, Ghana, Togo and Sierra Leone** which had the highest representation. Other countries included; **DRC, Burundi, Kenya, Uganda, South Africa and Malawi.** The participants included representatives from Ministries of health from some West African countries

(The Gambia), palliative care national associations, hospices and palliative care service sites, academic institutions, individual palliative care champions, Research students, among others.

Although the meeting targeted West African countries, it was also open to and was attended by other regions that were interested in the status of palliative care in West Africa.

APCA fully sponsored 12 stakeholders from West Africa to participate in this meeting.

3) METHODOLOGY

The meeting was interactive and participatory to ensure that all members were able to come up with the best ideas and solutions that are tailored to West Africa. The moderators of the meeting majorly used group discussions and plenaries to be able to derive the information required to meet the objectives of the meeting.

4) THE STATUS OF PALLIATIVE CARE IN SELECTED WEST AFRICAN COUNTRIES

Below is the status of palliative care in seven of the eight West African countries as presented with power points by representatives of each country at the meeting; that is; Togo, Nigeria, Ghana, Cote d'Ivoire, Cameroon, The Gambia and Sierra Leone. Each presentation was followed by Questions and Answers session.

COUNTRY	PALLIATIVE CARE STATUS	CHALLENGES	PC PRIORITY NEEDS
Togo *(Prof Belo)*	- There is no national association in place - PC integrated in revised draft of first NCD policy and Strategic plan of Togo (2012 - 2015). - 2 people trained with support from APCA and HAU - 50 health professionals trained locally. - PC medicines are available; since 2014 national pharmaceutical authority supplies private pharmacies and private wholesalers.	- Coordination and management of the commands by CAMEG (The national Agency of Essential Medicines Procurement) of PC medicines including oral morphine. - Lack of stem notebooks for the traceability of the orders and the use of opioids. - Needs assessment of morphine derivatives nationwide has not been	- Education and training - Medicines availability

COUNTRY	PALLIATIVE CARE STATUS	CHALLENGES	PC PRIORITY NEEDS
	- All teaching and regional hospitals have a Psychologist position. - Religious leaders are allowed at the patient bedside upon request by patient or caregiver. - Partnerships between APCA and IAHPC among others	done. - There is need to demystify morphine prescription among health workers and the general population.	
Nigeria *(Prof Olaitan)*	- National Association (HPCAN) exists and is functional - PC is included in the National Cancer Plan 2008 - 2013 - A few people trained in specialist PC currently. - Over 100 trained in Uganda on the Health Professional Initiators course. - There are on-going trainings locally for health workers - Various models are used to deliver PC services - Morphine is available	- Lack of National/state coordination and funding - Lack of donor support - Poor support for HPCAN - Few trained health professionals - Lack of public education on PC - Late referrals to available services	- Coordination - Education and training.
Ghana *(Dr. Mawuli)*	- National Association exists and is functional - There are trained PC teams and individuals scattered across the country -	- Strict control and regulation on opioids - Medical information systems to capture medication e.g. HAMS - There are no palliative care indicator to measure and track performance	- Coordination - Education and training.

COUNTRY	PALLIATIVE CARE STATUS	CHALLENGES	PC PRIORITY NEEDS
		- Claims reimbursement - - Levels of prescription	
Cote d' Ivoire *(Prof Beugre Kouassi)*	- National Association exists and is functional - Palliative care drugs are available in the country - There are trained Health professionals and training materials developed. - Various tools to improve quality of care and management are in place. - Service delivery is majorly in clinical setting although there are community CBOs that provide the service. It is majorly urban based. - There is some palliative care offered for Cancer as well.	- Definition of concepts - Socio-cultural attitude - Government commitment - Coordination of PC activities - Actors implication - Limited resources	- Education and training - Medicines availability
Cameroon *(Dr. Jonah Wefuan)*	- Has a national palliative care association that is fully functional - Health professionals have been trained across the country - Morphine is available in the country and is distributed to health units that have the modalities in place.	-	- Education and training - Coordination
The Gambia **(**	- National Health Policy frame work in place to integrate PC into hospital health care services. - Availability of essential medicines - Integration of PC in medical and nursing schools	- Inadequate trained human resources in place - Inadequate resources - Implementation of the National Action Plan for PC not implemented as	- Education and training - Medicines availability

COUNTRY	PALLIATIVE CARE STATUS	CHALLENGES	PC PRIORITY NEEDS
	- (University of The Gambia incorporated PC into Pharmacy training curriculum) - Awareness raising through PC material dissemination - PC/ Homebased care manual in place	planned.	
Sierra Leone *(Dr. Samba Ceesay)*	- There is no national policy on PC in place, but it is integrated into Care and treatment of HIV/AIDS - There is a palliative care association (Sierra Leone PC Association) - Opioids are available although on limited scale for patients that are referred to Shepard's Hospice - Over 23 health centres are providing PC services - There has been some PC training for the health workers in these health facilities - Since 2011, final year medicine students must spend two weeks of placement in the community providing PC services		- Education and training - Medicines availability

5) WEST AFRICA REGIONAL PALLIATIVE CARE NEEDS, STRATEGIES TO RESPOND TO THE NEEDS, REQUIRED RESOURCES AND POTENTIAL RESOURCE PROVIDERS

GROUP #1

PC Priority needs	Proposed Strategy	Resources Required	Potential Source of Support
Policy	Involve/engage members of parliament	MOH to lobby with relevant MPs	Relevant MPs
Education and training of health workers	Integrate in curricula of Health Institution public health Education Social mobilisation Network Association of PC	Funds Technical support/Expertise	Gov't NGO's WHO
Medicines availability	Policy to allow importation of Opioids Encourage local and region production of opioids	Policy Technical support/Expertise Funds	Policy makers (Gov't) International Organisations
Share best practices in PC	Study Visits to relevant countries	Funds	NGO Gov't APCA WHO
Integration of PC into the National Insurance	MPs	Funds	Gov't
Home based care	Using Community health Nurses, Village Health Workers	Funds	Global Fund Gov't

GROUP #2

PC Priority needs	Proposed Strategy	Resources Required	Potential Source of Support
Education	I) Educate leaders and volunteers at community level II) Educate healthcare workers III) Educate other professionals IV) Improve advocacy and policy writing V) Research	a) Curricula b) Training of Trainers c) Dedicated time d) Financing	- APCA - Local Associations - Celebrities (Public)
Medicines Availability and affordability	i) Increased government commitment through education/advocacy ii) Local production	a) Incentives for local production b)	- Community /local associations - APCA

GROUP #3			
PC Priority needs	**Proposed Strategy**	**Resources Required**	**Potential Source of Support**
Education and training	Short term Long term	HR Institutional PC Create new PC centers	International and local Donors Regional solidarity funds Budget support

GROUP #3			
PC Priority needs	**Proposed Strategy**	**Resources Required**	**Potential Source of Support**
Coordination	Regional National	Governments coordinating representatives Regional PC group Committed HR PC desk/focal person	Government support
Availability of essential medicines	1. Accessibility A) Geographical B) Financial 2. Controlled local production and distribution	HR trained pharmacists Palliative care team	Pharmaceutical companies Media companies Government support

6) PRIORITY AREAS BY COUNTRY

SN	COUNTRY	# OF REPS	PRIORITY AREAS
1	Nigeria	5	- Coordination - Education and Training
2	Ghana	7	- Coordination - Education
3	Sierra Leone	1	- Education and Training - Medicines Availability
4	Cote d' Ivoire	4	- Education and Training - Medicines Availability

5	The Gambia	4	- Education and Training - Medicines Availability
6	Cameroon	2	- Education and Training - Coordination
7	Togo	1	- Education and Training - Medicines Availability
8	Senegal	2	- Medicines Availability - Coordination - Education and Training
9	Burundi	1	- Education and Training - Medicines Availability
10	DRC	1	- Medicines Accessibility - Education and Training

7) RECOMMENDATIONS FOR NEXT STEPS

i. Develop a model training centre for palliative care education

ii. Train health care professionals who can work in their own area

iii. Advocate with the West Africa governments for a PC training school in West Africa with support from HAU and APCA, who can share some of the materials that West Africa can adapt with technical support from APCA in the training and development of materials.

iv. APCA needs to create a presence in West Africa, to support the 15 countries that are there.

v. Utilize the English speaking countries in West Africa to support the Franco phone countries

vi. Liaise with APCA to negotiate for support in West Africa since it is not well supported by development partners

vii. There is need to strengthen palliative care national associations in West Africa as they have a big role to play in PC development

viii. The 6th APCA Triennial conference should be held in West Africa as a major advocacy and awareness raising activity to boost PC in West Africa.

8) EVALUATION OF THE MEETING

The meeting was attended by 37 participants although only 19 participants participated in the evaluation to assess the meeting. Below is the summary of the feedback that was received from the participants;

The meeting

Of the 19 participants that assessed the meeting, 52.6% strongly agreed that the meeting lived up to their expectation and that the objectives of the meeting were clear to them. Participants remarked that the meeting was well organized and coordinated.

36.8% of the participants strongly agreed that the content of the meeting was informative appropriate and relevant to their work, while 63.2% agreed. On the other hand 55.5% strongly agreed that they will be able to use the information gotten from the meeting, while 44.4% agreed to that statement. Some of the participants felt that the program of the day was not clear as the meeting did not follow the agenda that was laid out.

Participants were not happy about the time management as the meeting was meant to be a half day but went till evening. However, there was a major interruption by the Minister's session, where all participants were required to attend till after the Prime Minister left.

The presenters/facilitators

42.1% strongly agreed that the presenters were proficient while 57.9% agreed. This was an excellent rating as it was very important that the meeting was well facilitated and a high level of professionalism was required to ensure the meeting outcomes are met.

Conference facilities

In terms of conference facilities, 52.6% strongly agreed that the conference facilities were adequate and appropriate that day, 42.1% agreed while 5.3% strongly disagreed. *Conduct of APCA and WHPCA staff*

47.4% strongly agreed that staff conducted themselves professionally, while 52.6% agreed.

Conference organizers

While 50% strongly agreed that Events Management acted professionally and was supportive that day, the other 50% agreed to the statement.

Lessons that participants picked from the meeting

- Palliative care exists in West African countries and has done so for many years, for example Senegal has had a PC for 16 years
- Francophone countries have strong PC associations, although there is need for a palliative care centre/training school in West Africa.
- Importance of champions, education and coordination in PC
- The status and experiences and challenges of palliative care in other countries
- Palliative care is a human right and is not a one man show, but all must be involved, and different disciplines have different roles to play including the media.
- NGO opportunities in palliative care
- PC focus areas as per WHO priorities
- The role of the African PC regional network

Overall, based on the evaluation, the meeting was rated well above average and members generally agreed that it was a meeting that was long overdue and was very important for the development of palliative care in West Africa.

It is anticipated that West Africa will be able to act on the WHA resolution on strengthening palliative care as a component of comprehensive care throughout the life course, and ultimately ensure palliative care for all in West Africa, if the meeting outcomes are implemented.

9) APPENDICES

i. Appendix 1; Meeting agenda

ACCELERATING PALLIATIVE DEVELOPMENT IN WEST AFRICA MEETING, TUESDAY AUGUST 2016, 8:00 AM – 10:30 AM,

Time	Presentation	Presenter/Facilitator
8:00 – 8:15am	Introductions and background to meeting	**Dr Emmanuel Luyirika,** Executive Director, APCA
8:15 – 9:15am	Status of Palliative Care in West Africa by country: progress, best practices, challenges, and gaps: - Nigeria (Prof. Olaitan Soyannwo) - Ghana (Dr. Mawuli Gyakobo) - Sierra Leone (Gabriel Madiye) - Cote D' Ivoire, (Prof. Beugre Kouassi) - The Gambia (Dr. Samba Ceesay) - Cameroon (Dr. Jonah Wefuan) *These countries have a level of PC)*	**Prof. Olaitan** *8-10minute presentations*
9.15 – 9.30	Palliative Care Status in other West African countries; - Togo (Prof. Belo) *These countries have very limited PC)*	**Prof. Olaitan** *Open discussion*
9:30 – 10.00am	Priority needs for the integration of Palliative care in health systems in West Africa Opportunities and strategies to implement the priorities Identify resource requirements and sources for integrating PC in West Africa health systems	**Dr. Wefuan** *Group discussions/fill out template*
10:10 – 10:20am	Plenary discussions on Priority needs, strategies and resources requirements by country	**Dr. Wefuan** *Each country walk through 2 priorities*
10:20 – 10:30am	Way forward and closure of meeting	**Prof. Olaitan**
	TEA BREAK	

ii. Appendix 2; List of participants

ACCELERATING PALLIATIVE CARE IN WEST AFRICA – INTEREST GROUP HELD AT SPEKE RESORT, MUNYONYO ON TUESDAY 16 AUGUST 2016

	NAME	DESIGNATION	INSTITUTION	COUNTRY
1	Dr Jonah Wefuan	Consultant Physician	Greenfield Dynamic Medical Center, Bamenda	Cameroon
2	Dr Esther Dina Bell	Medical Oncologist	Douala General Hospital	Cameroon
3	Prof. Olaitan Soyannwo	Consultant Pain/Palliative Care	University College Hospital/Centre for PC Nigeria	Nigeria
4	Dr Kolawole Israel	Palliative care	U.I.T.H, Ilorin	Nigeria
5	Durojaiye Abiola Omocomi	Nurse	University of Ilorin	Nigeria
6	Dr Samba Ceesay	Ag. Director of Health Services	Ministry of Health	The Gambia
7	Dr Aka Dago Akridi Hatase	Vice Chairman	ASPCI	Cote d' Ivoire
8	Dr Siagbe Soungole	Coordinator	ASPCI	Cote d' Ivoire
9	Prof. Beugre Kouassi	Board Chairman	ASPCI/APCA	Cote d' Ivoire
10	Prof Plo Kouie Jeannot	General Secretary/Member	ASPCI/APCA	Cote d' Ivoire
11	Boubacar Pouqho Sow	Medicine	MAADJI	Senegal
12	Oulimate Drop Sow	Nutritionist	MAADJI	Senegal
13	Dr. Belo Mofou			Togo
14	Mr. Gabriel Madiye	Executive Director	Shepard's Hospice	Sierra Leone
15	Dr Benedict Okre Que	Family Medicine Resident	Tetteh Quarshe Memorial Hospital	Ghana

	NAME	DESIGNATION	INSTITUTION	COUNTRY
16	Dr Edwina Addo Opare – Lokko	Palliative care Physician	Kole Bu Polyclinic/Ghana Health Services	Ghana
17	Dr Omoyeni N. Eunice	Palliative care Physician	University College Hospital, Ibadan	Ghana
18	Dr Mawuli Gyakobo	Family Physician	Ghana Health Services	Ghana
19	Dr Anthony Davor	Staff Champion- Pain free Hospital Initiative	Bulga	Ghana
20	Dr. Rexford Quarshie	Family Medicine Resident	Tetteh Quarshie Memorial Hospital	Ghana
21	Dr Mary Opare		Ghana Palliative Care Association	Ghana
22	Dr Micheal Owasa – Arish	Family Physician	Konfo Anokye Teaching Hospital	Ghana
23	Dr Anita Eseenam Agbeko	Surgeon	Korufo Anokye Teaching Hospital	Ghana
24	Josephine Asitiba	Nurse	Kakamega Country Hospital	Kenya
25	Caroline Sabulei	Oncology/PC Nurse	Moi Teaching and Referral Hospital	Kenya
26	Suzan Kipsang	Medical Social Worker	Moi Teaching and Referral Hospital	Kenya
27	Daisy Rottich	Clinical Officer	Moi Teaching and Referral Hospital	Kenya
28	Phanice Jepkemoi	Palliative Care Nurse	Moi Teaching and Referral Hospital	Kenya
29	Lecareux Yupizh	Student	Hospice Africa Uganda	Uganda
30	Dive Sylvia	Nurse Trainer	Hospice Africa Uganda	Uganda
31	Timothe Valin	Specialist Intern	Hospice Africa Uganda	Uganda

	NAME	DESIGNATION	INSTITUTION	COUNTRY
32	Muhigirwa Josephine Cizza		ASOBABU	Burundi
33	Matafwar Albertina	Nurse	MAGNIFILANT	DRC
34	Penelope Mathi	Social Worker	South Africa Hospice - Wits	South Africa
35	Immaculate Kambiya	Nurse and Palliative Care Coordinator	Ministry of Health	Malawi
36	Eduardo Garracoa	Research Assistant/Atlantes Prog.	University of Navarra	Spain/France
37	Frank Stadler	PhD Student	Griffith University	Australia