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# Interview with Palliafamilli

Improving access to palliative care in the Democratic Republic of Congo



# Interview with the President of the Palliafamilli Association from the Democratic Republic of Congo

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This interview was conducted in August 2016 with Anselme Mubeneshayi Kanaga – President of the Palliafamilli Association / Advisor of the National Palliative Care Association of Congo – regarding the experience of Palliafamilli, an association that successfully created a national dynamic for promoting and improving access to palliative care in the Democratic Republic of Congo (DRC).

## Could you please introduce Palliafamilli and the rationale behind its creation?

Our work started on a voluntary basis, and was provided by health professionals who recognized the importance of assisting patients suffering from chronic diseases such as cancer, HIV/AIDS, diabetes or stroke. As there is no universal health coverage in DRC, the vast majority of patients do not have access to treatment and simply go back home when they receive this kind of diagnosis. As a result, patients consult the nurse or the doctor from their neighbourhood. This is how we realised that providing a service in patients' homes was essential. Therefore, we built a network between physicians, nurses, physiotherapists as well as psychologists in order to assist these patients.

This is how "Palliafamilli" was born – meaning palliative care for the family and with the family. Indeed, family members are key in accompanying patients by relieving them from some symptoms and by providing emotional support.

## According to you, what are the greatest challenges regarding cancer control in DRC and specifically regarding access to palliative care / pain management for cancer patients?

In the beginning, we had many issues regarding opioids, as access was refused. We only used these drugs to treat acute pain, for example in the context of a surgery or traumas. But nowadays, thanks to our movement, the government has understood that opioids should also be used for pain management of cancer patients.

However, opioids are classified as illegal drugs. We therefore need to raise awareness of the government on this aspect. The Ministry of Health is now engaging in promoting access to opioids. Therefore, while this was a challenge five years ago, we now see a change towards a liberalisation of access to opioids. We currently work with the Belgian Ministry of Health to launch a programme dedicated to promoting access to opioids. This programme will be launched in September.

Regarding cancer control, the greatest challenge is the lack of reliable epidemiological data. There is no cancer registry, and as we cannot measure the amplitude of the issue, it is difficult to plan access to medicines, radiotherapy as well as other treatment.

Moreover, there is no established cancer centre. Patients who have the financial means go to India or Europe for treatment. This issue is prevalent along the whole continuum and above all at the diagnostic level, which requires qualified personnel and appropriate equipment. This is a major issue, and explains why many patients are diagnosed far too late for effective treatment. This is when palliative care is needed.

The majority of patients that we take care of are cancer patients. Contrary to HIV for which many efforts led to the availability of treatment, this is not the case for cancer. Before, we were saying that HIV/AIDS kills, but now we say that we can live with HIV. However, for cancer, there are still a lot of efforts to be made.

**Bringing civil society together and collaborating with national authorities seem to have been key factors in the creation of a national association. Could you please tell us more about this nation-wide collaboration effort?**

Palliafamilli was created in 2009. When speaking with other NGOs and hospitals we realised that these needs were extremely important. As a result, we organized a first meeting in 2010 which allowed us to bring together multiple stakeholders, namely hospitals, academia, associations as well as other organisations such as the Red Cross. We agreed that we needed advocacy with the national authorities to find out the best way to initiate a policy for promoting, developing and ensuring access to palliative care.

This is when we thought that it would be relevant to go and see how palliative care was being implemented in a neighbouring country. The whole Palliafamilli team travelled in 2011 to Anglophone Africa to visit Hospice Uganda in order to see what they were doing. We thought that it would be better to learn from a neighbouring country as they experience a similar context. We thought it was better to learn from their model to see how they developed access to palliative care. We also encouraged Hospice Uganda to come to Kinshasa and discuss with the Ministry of Health to initiate a discussion on how to improve access to care. In 2012, we held an awareness day at the Ministry of Health with Hospice Uganda and the African Palliative Care Association. And, in 2013, a delegation from the Ministry of Health went to Uganda to learn from their experience. When they came back, they were convinced by their approach and decided to act for cancer patients.

In 2013, we organised a first congress on palliative care with the participation of colleagues from Europe and Africa, including from Congo-Brazzaville, in order to ensure that health professionals can meet each other and reflect on best practices. Subsequently, we sent 10 people to Uganda for training.

The government increasingly showed interest in developing a national policy on palliative care. In 2015, we organized a second congress and we started to discuss the creation of a national association for palliative care, which was created immediately after the congress.



Palliafamilli headquarters in the city of Mont-Ngafula / Kinshasa DRC

### **If another country wants to initiate a similar movement, what would be your advice? What was your recipe for success?**

Our recipe was to involve the national authorities as much as possible. Politicians are often skeptical, so we invite them to our meetings to show them the concrete issues we are facing in our daily work. We invited the ministers and their teams.

We also demonstrated that we were the “*voice of the ones who don't have any voice*”. Then, we thought: “*we don't need to reinvent the wheel. We learn from what is done elsewhere and we adapt it to our own context.*” We say “*No one is a prophet in his own country*”. This is why we asked Hospice Uganda to show us their model. What really made the difference was that representatives of the Ministry were able to travel to Uganda to see how the model was being implemented. It was not relevant to go to Europe, the context being too different. This visit to Uganda really helped raise awareness of the Ministry officials.

### **What are the next steps for developing palliative care in DRC?**

The association is basing its actions on three pillars: advocacy, training and awareness raising.

Regarding advocacy, we aim to promote access to opioids, including substance control and all legal aspects. We also work towards obtaining an official recognition of health professionals who specialize in palliative care. It is important that this specialisation is institutionalised at the national level.

As for training, in 2017 we will be launching a new diploma on palliative care at the school of medicine at the University of Kinshasa, in partnership with Médecins du Monde Switzerland and with the support of the Universities of Lyon, Montreal and Geneva. It is very important that this programme be adapted to our realities, cultural and spiritual, as well as the context of access to care. We also want to include palliative care in the initial training of physicians and nurses. We started by an initiation module of 15 hours for physicians. Then, those who want to specialise in palliative care can enrol in the Diploma. They will be future leaders in palliative care in the country.

Finally, our third objective is to raise awareness. In 2017, we will organise a whole week dedicated to palliative care. We will visit hospitals, universities and nursing schools to explain the importance of palliative care to young physicians and nurses.

This is our strategy to ensure the sustainability of access to palliative care in the country.

**Are you developing other actions in Francophone Africa? What do you think about a regional collaboration, for example with a view to replicating the DRC experience in other countries in Francophone Africa?**

Médecins du Monde Switzerland contacted us to help implement the same approach in Cameroon. I was there a few months ago to facilitate a training workshop. Participants were doctors, nurses, academics, and anthropologists. After 2 days of training, we invited the Dean of the School of medicine as well as the Minister and we explained the model implemented in Kinshasa. I am in regular contact with our correspondent in Cameroon to assist him with advocacy.



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