

# Palliative and end-of-life care in Zambia

-A case study on urban and rural settings-

Year: 2010

Place of fieldwork: Zambia

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## **Research background**

According to the UNAIDS report, in 2009, an estimated 1.3 million AIDS-related deaths occurred in sub-Saharan Africa. WHO estimates that 500,000 people die from cancer annually in sub-Saharan Africa. In this context, the concept and practices of palliative medicine have been boldly introduced into sub-Saharan African countries by international organizations and NGOs in recent years. Several initiatives are underway to promote the development of palliative care in sub-Saharan African countries. In Zambia, at least 12 organizations provided palliative care services such as hospice and home-based care in 2010.

WHO defines palliative care as an approach that improves the quality of life of patients and their families who face problems associated with life-threatening illness, by providing pain and symptom relief, spiritual and psychosocial support from diagnosis to the end of life and bereavement. The autonomy of patients is one of the key concepts, and palliative care should thus be implemented on the basis of the social and cultural settings. Thus far, however, the palliative care that has been introduced to African countries is predominantly modeled on Western culture.

## **Research purpose and aim**

The purpose of this study is to survey and analyze the current situations of two settings that are related to palliative care. One is the current situation of hospice care in urban areas that has been introduced by Western NGOs and missionaries. The other is the end-of-life care in rural settings. Finally, I would like to consider the applicable palliative care that people expect and its challenges.

## **Results and achievements by fieldwork**

This study was carried out at a hospice in the capital city, Lusaka, and a village in the rural area of the eastern province in Zambia from December 2010 to January 2011. First, at the hospice, data were gathered by interviewing patients' families, medical experts, and care-givers. Second, interviews and participant observations about the end-of-life care were carried out in the rural village.

The hospice has been advocating the promotion of palliative care for patients who have HIV/AIDS and cancer. There is a hospital near the village, however, it has not provided medical treatment that includes palliative medicine.

Most hospice clients do not recognize the difference between the hospice and general medical facilities. There are some options related to the care and facilities for people in the terminal stage, however, under most conditions, the choices are dependent on the economic states of patients and the decisions of medical staff. This often brings about a sense of guilt and defeat to patient families.

In the rural village, there have not been enough medical pain control systems to provide palliative care. Nevertheless, intensive care from families and villagers was observed. For example, some of them stayed with the patient constantly, took care of meals, and kept them company. It seemed quite probable that this care system relieved the psychosocial pain of the patients and their families. However, some families wanted aggressive medical treatment to be provided at the hospital to prolong the patient's life to the furthest extent possible.

### **Implications and impacts on future research**

In the future, I would like to examine the social network that encompasses both urban and rural areas. It is important to note that people move frequently between urban and rural areas. Some patients who use an urban hospice rely on rural relatives who take care of them. Further research will help to find new approaches, emphasizing their socio cultural aspects.



In-patient ward of a hospice in Lusaka



Handmade crutches in a rural village



Poster of the African Palliative Care Association (APCA) meeting in Lusaka