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# Palliative Care Practices of Community Health Workers and Professional Nurses

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in Limpopo Province,  
South Africa

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## I ABSTRACT

In Sub-Saharan Africa, shortages of health workers have negatively affected health care due to the severity of the HIV/AIDS epidemic as a result of migration to urban areas and to private institutions. As a result, CHWs and professional nurses provide needed care in the community. This pilot study sought to understand palliative care practices and challenges faced by CHWs and professional nurses as

**Without more health care workers, the burden of care will be continue to be placed disproportionately on nurses and community health workers.**

well as the feasibility and cultural appropriateness of the Palliative Care for

Dignified Dying survey in the Vhembe district of Limpopo Province, South Africa. Through the use of focus group interviews, common themes were identified: Ubuntu and spirituality, direct care, comfort, self-care, and advocacy for bereaved children. This pilot study provided significant evidence that additional hospice facilities are needed in Vhembe district. Due to the HIV/AIDS epidemic and loss of cultural traditions resulting from loss of entire generations, now is a prime time to begin to establish a more prominent hospice community.

## I BACKGROUND

The World Health Organization estimates that 20 million people across the world need palliative care at the end of life. Palliative care is an interprofessional care model used to guide end-of-life care for people in advanced stages of a life-limiting illness of any type [1]. Much of what is known about delivery of palliative care stems from the United

States (US) and the United Kingdom (UK). Although the arrival and dissemination of anti-retrovirals (ART) in South Africa has extended life expectancy for people living with the HIV/AIDS virus, the need for palliative care still exists.

care providers [2]. In 2013, there were 0.78 doctors per 1,000 people in South Africa. In order to provide access to ART, there must be at least 2.5 health care workers per 1000 people. Without more health care workers, the burden of care will be continue to be

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As HIV positive patients develop AIDS-related diseases, the need for health workers who can deliver skilled care has risen dramatically. Unfortunately, shortages of health workers (ie. doctors, nurses, pharmacists, etc.) have negatively affected health care in sub-Saharan Africa, especially in South Africa due to the severity of the HIV/AIDS epidemic there. Shortages occur because health workers leave rural areas to go to urban areas and from public to private institutions, which can skew the distribution of health

placed disproportionately on nurses and community health workers (CHWs) [3]. CHWs and professional nurses provide needed care in the community. For over 60 years, tasks formerly under the domain of nursing have been shifted to CHWs [4]. CHWs provide much needed care in the community, extending the reach of the nurses beyond the clinic [5]. CHWs also help to improve the human dignity and quality of life of people living with HIV by working to reduce HIV stigma and promoting a sense

of belonging within their communities [6]. Therefore, our pilot study sought to understand the palliative care practices of the CHWs and professional nurses, as well as their challenges when providing care to their patients. Additionally, we wanted to know the feasibility and cultural appropriateness of the Palliative Care for Dignified Dying survey in the Vhembe district of Limpopo Province, South Africa.

## RESEARCH QUESTIONS

1. What are the palliative care practices of CHWs?
2. What are the palliative care practices of the professional nurses?
3. What are some of the challenges in their practice?



Photo taken in South Africa.  
By Aubrey Doede.

## METHODOLOGY

A descriptive survey design was used to collect information about the CHWs and professional nurses located in the Vhembe district of Limpopo province. The professional nurses were asked to complete the Palliative Care for Dignified Dying (PCDD) survey. Nurses were asked to rate each intervention on the survey using a 4-point summative rating scale on importance to their practice (1 = not at all important to 4 = very important) and on how knowledgeable they thought they were on the intervention (1=not all knowledgeable to 4=very knowledgeable). The higher the importance score, the more important the intervention was to their practice. The higher the self-reported knowledge score, the higher the knowledge about the intervention. All participants were Venda and female. Of the participants involved in the study, 90% of them worked for non-governmental organizations (NGO's), and 10% worked for the South African Department of Health. After the completion of the survey participants

completed a 4-item feasibility measure (ease of use, time for survey administration, understandability, and cultural appropriateness). The paper surveys took approximately 45-60 minutes to complete using a pen.

**Questions asked in the focus groups were developed specifically to allow the use of storytelling as a method of gaining information on palliative care practices.**

Information about palliative care practices of CHWs and professional nurses in Limpopo Province, South Africa, was also gathered through the use of focus groups. Questions asked in the focus groups were developed specifically to allow the use of storytelling as a method

of gaining information on palliative care practices. Storytelling is an effective way to flesh out information on a subject area and was particularly useful in this pilot study in which one major goal was to evaluate the feasibility

of conducting further research in the province. Additionally, storytelling is a culturally appropriate interaction for the Venda people of Limpopo Province. Questions included, 'How does the South African virtue of Ubuntu contribute

to your delivery of care?', 'What traditional medicines including herbs and faith healing are part of your practice?', "Tell us about a time when you provided palliative care", and 'How do you take care of yourself to

promote resiliency and avoid compassion fatigue?'. Each focus group took about an hour to complete, and from the focus groups, common themes were identified to guide further research.



Photo taken in South Africa.

We had a tailor make culturally accurate costumes for us that we wore for our presentation at the University of Venda. The people in the picture from left to right are Lillian Ware, Jennifer Stueve, and Mary Kay O'Brien.



## RESULTS AND OUTCOMES

The common themes that were expressed during the focus groups were the following: Ubuntu and spirituality, direct care, comfort, self-care, and advocacy for bereaved children. The CHWs related how they embody Ubuntu in their practice by showing kindness, love, respect, and compassion to their patients and establishing a therapeutic relationship with their patients. They also offered prayer for their patients and families. The nurses indicated that through the embodiment of Ubuntu, they were compelled to support their patients through educating the patients about the disease process and instilling hope instead of despair.

Direct care is one of the essences of health care. The CHWs cleaned their patients, washed clothes, and completed cooking and yard work. They also cleaned wounds and changed dressings. Providing comfort within the CHWs' scope of practice included addressing not only the

physical aspects, but also the emotional and spiritual aspects of the patient. The CHWs stated they offered a listening ear to their patients and talked about God. Nurses arranged for their patients to receive pastoral visits and provided pharmacological agents to relieve their patient's pain, although the supply of pain medications was limited.

It is important for individuals to take care of themselves, especially when caring for others is a component of their occupation. We wanted to know how the CHWs and professional nurses implement self-care, and we learned that many of them pray and attend church, as well as receive emotional support from their spouse and or family members. One CHW mentioned that she received training to develop coping skills. The professional nurses mentioned the use of professional counseling, attending nursing conferences, and having the support of family.

A life-limiting illness, such as HIV/AIDS is not isolated to the person that is sick, but instead the family is



Photos taken in South Africa.  
By Aubrey Doede.



also deeply affected. After a parental figure passes away the bereaved children need an advocate to make sure they are able to live in a safe environment in which their needs are met. Unfortunately, orphaned children are a big issue. According to UNICEF there are estimated to be 3.7 million orphan children in South Africa, and nearly half of these children have been orphaned due to HIV/AIDS-related diseases. There are also many children living with sick and bedridden caregivers, and approximately 150,000 children are believed to be living in child-headed households [7].

Based on the focus groups and PCCD surveys, the CHWs and professional nurses indicated there is a lack of hospice facilities in the Vhembe district, which leaves non-familial palliative care to them. Care of the patient's family proved to be a significant part of palliative care provision, as well as providing emotional and spiritual support. In addition, there is an unreliable supply of pain relief medications.

## DISCUSSION AND CONCLUSION

This is the first time palliative care practices of health care workers in a rural area outside of the US or UK has been studied. Families in Limpopo Province, South Africa, have experienced a loss of cultural knowledge about end of life and post-mortem care. CHWs and professional nurses are providing palliative services for patients and their families. Palliative care education is needed. This pilot study provided significant evidence that additional hospice facilities are needed in Vhembe district. During our interviews and focus groups with CHWs and professional nurses, the need for hospices was expressed. However, securing funding presents a challenge. With the decreased life expectancy of South Africans due to the HIV/AIDS epidemic and loss of cultural traditions resulting from loss of entire generations, now is a prime time to begin to establish a more prominent hospice community.

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