Experiences of HIV and AIDS patients and families regarding palliative care in an urban care centre in Buffalo City

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Thank you

• PEPFAR and New Partners Initiative
• Sophumelela
• HPCA (Sue and Kath)
Background
Research Setting

2008 – 2012  Dignity House
a palliative care centre in Buffalo City
Introduction

- With 9 beds and 2 cots, the centre provided palliative care for around 7 new persons each month.
- Bed occupancy of 80%
- Death rate of 28%
Research Question

What are the lived experiences of patients with HIV/AIDS and their families receiving palliative care in a care centre in Buffalo City?
Research Methodology

• Qualitative

• Phenomenological approach

Research Design

• Exploratory

• Descriptive

• Contextual
Ethical Considerations

The following principles were observed:

— Confidentiality and anonymity
— Fair treatment
— Beneficence and non-maleficence
— Privacy and consent
— Informed, written consent was obtained from all participants
Population and Sampling

• **Population:**
  all persons diagnosed with HIV/AIDS, being cared for in a palliative care centre

• **Sampling:**
  Purposive sampling technique
  Inclusion criteria:
  - Admitted to the care centre for longer than 3 weeks
  - Able to speak English
Data Collection and Analysis

In depth interviews were recorded, transcribed verbatim and organized into themes and sub-themes using open coding and analyzed with the help of an external co-coder.
Description of Results by Themes

1. Care received was holistic

- “the people here have a holistic approach ... When you need healing from any disease you need prayers, good care, love and people who understand ...”

- “… it was that close, close care that I wanted”
1.1 Dignity, support, encouragement, hope and autonomy

• “...it’s the approach, even they talk with you, the nurses smile always”

• “Now I understand ...” ...

• FOOD

• “We are asked, ‘What would you like to eat?’ What do you like?”

• “I can eat whatever I like!”
2. “Unique” environment

• “It’s the hospitality ... The cleanliness of the place especially the bathrooms”

• “The [staff] are warm hearted, the love that you get here ... they treat you well. They make you to feel that you are ok ... They make you feel that they own you, you are theirs. You belong to them.”

• “Here you stand in front of me; you wait with water. So I can’t even throw [the pills]. Because you want me to be well.”

• “There was somebody with me all the time.”

• “Always with nice clean clothes and I was feeling fresh everyday”...
3. Traumatic past experiences

- “... the care was wonderful because I could go to the toilet whenever ... I was not bound by [their routine]”
- “I had to go frequently to change him. He was wet, wet. But here it was nice to him.”
- “Even if you just maybe wee wee no one will shout at you. Nurses they will help you about that”
- “The way the staff look after you here. They don’t shout at you but they explain things” ...
- “I couldn’t talk to anyone. They were always busy”
- “ARV times were haphazard.”
4. Patients experienced fear, hopelessness and a spiritual void before admission

• “I was very, very sick ... my brother was so scared. I have a belief that I would have died.”

• “I was very dizzy, I can’t even see what was going on with me ... I was just feeling down”...

• “Well, I was afraid at first. I didn’t even want to come because there is this thing that when you are admitted in a hospice you are about to die. So I was afraid.”
5. Family experienced relief when the patient was admitted

- “when your family is sick you lose that hope. You just give up everything. You just feel alone, you don’t have that support”

- “[We didn’t know]...how to treat them and how to love them”

- “I am not stressed like before. It was a big relief for him to come here.”
“But because what people here did, I need you to see that what you are doing here changes lives, their perception of this place called hospice. I’m sure it is not me alone that thinks these things about a hospice that you go there to die. But by what you did, I got healed ... in that Dignity House people get healed, people get saved. What you did here it is making us want to get better. It’s an encouragement. By closing this place many people will suffer especially those who are HIV positive. I tell them that at that place they will help you ... They help you until you are better”
Broyard (1992) wrote, “To the typical physician, my illness is a routine incident in his rounds, while for me it's the crisis of my life. I just wish he would give me his whole mind just once, be bonded with me for a brief space, survey my soul as well as my flesh, to get at my illness, for each man is ill in his own way. I'd like my doctor to scan me, to grope for my spirit as well as my prostate. Without some such recognition, I am nothing but my illness.”
Before ...???

Half way through ... And after
There’s the evidence!

Thank you