

# Emotional support of older persons caring for family members

Prof Sebi Lekalakala-Mokgele  
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# Background

- Concept of formal care and informal
- Economic status impossible to support formal care
- Greying of boundaries between formal and informal
- More older persons taking care of younger due to HIV/AIDS
- Some also took care of own ageing sick parents
- Research : taking care of sick and dying has physical as well as emotional burden
- **Who care for these elderly carers?**

# Purpose

- Describe the experiences of older persons caring for sick and dying family members
- Encourage dialogue to support the elderly taking care of sick and dying family members

# Methods

## Design

- Qualitative
- Qualitative
- Explorative
- Contextual
- Descriptive

## Sampling

- Purposive
- Sampling size
- 10 Females
- All 65 and above

## Data collection

- In-depth interviews

# Ethics

- Study approved by MREC
- Consent sought and granted by participants
- Emotional support arranged (Psychiatric Nurse and pastor)

# Data Analysis

## Themes

- Emotional pain
- Loss of hope and helplessness
- Grieving and hiding tears
- Denial
- Bargaining
- What kept them going



# Emotional pain

- *“there’s nothing painful than hearing your mother screaming at night, when that pain comes in she was screaming and she would say “you know the way this pain is so severe, I wish you could remove this part” (73 years old female)*
- *“I was hurting, what was hurting me was the fact that I’m eating and she can’t ” (65 years female)*
- *“when you touch her leg she would scream, that voice is still on my mind, every time when I think about her and that cry, I don’t feel good at all, every time when I was taking care of her, I kept on asking myself why is she not getting better, because I’m doing everything possible but there’s no change” ( 78 years female)*

# Loss of hope and helplessness

- *“I could see that there was no longer hope, I was hoping that she would survive until the Christmas holidays but she passed away on the 22<sup>nd</sup> December” (65 year female)*
- *“I’m feeling helpless because I took care of sick people and not just one but a few, and they are all dead I’m left alone, from my elder brother to my mother, the last born in the family and my own child” (78 years female)*

# Helplessness

- *My children died within a short period of each other, the other one died in August and the other one passed away on the 16<sup>th</sup> December 2013, the one who passed away first she was very sick. I felt the pain later, asking myself a question, why did they die within such a close range of each other, but I said to myself maybe because he saw that I'm taking care of the sister, he was afraid to tell me that he's also sick, I felt so helpless (female 72 years)*

# Grieving and Hiding tears

- *“When I cry I was hiding myself from these grand-children, I told myself that I can’t cry because if I do, these children will also cry” ( 73 years, lost two children)*
- *“at that moment I didn’t want to show her that I’m hurting inside, I went to the toilet and I cried because I didn’t want to cry in front of her” ( 65 years, lost a daughter)*
- *“I was hurting a lot, the pain that I felt, when I was with her I was pretending to be strong but as soon as I leave her I cried, I felt the pain deeply, but if I’m with her I try to compose myself so that she cannot see that I’m hurting, when you are with her you try by all means to pretend and to downplay her thought of wanting to die at home” (79 years, lost an elderly mother)*

# Denial

Denial was more profound when children were involved

*“My son would say “mother, my wife, don’t worry, we all know that death is for everybody, you see me isn’t it” and we would say “yes we do” and he said “death is for everyone but what is important is that I must prepare everything before I leave, I must make things right at work, church and here at home” and I said “**you are not going anywhere**” I’d rather be the one who dies instead” and he replied “there’s no way, if it’s my time to die, how can you be the one who dies before me, if it’s time and then I have to go” (78 years old)*

# Bargaining

- *“God take me rather, replace this child’s life with mine, spare him so that together with his wife they will be able to raise their children, I’m already old, please take my life and spare my son” he was my only child, he did everything for me” (78 years old)*
- *“I kept on telling myself that she will be fine, time went by and it was approaching December, I said to myself why can’t she live until the end of December so that we can enjoy the December holidays” (65 years old)*

# What is clear

- Older persons have emotional burdens
- They have to deal with their emotional burdens
- They have no resources to assist them
- They will need assistance to enable them deal with their burden

# What do I take back ?

Let us have a dialogue



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