



# Qualitative Research work in palliative care

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# Ugandan patients' experiences of living and dying with Heart failure

# Background and study rationale

- Need for multidisciplinary and palliative care involvement in advanced HF.
- Patients' experiences and wishes should inform care .
- Lack of information on patients' experience of living with HF in Africa with a different pathological, clinical and social spectrum.
- Thus research that improves understanding of African HF patients' experiences needed to develop context specific guidelines in management of these patients.



## Research question



 What are the multidimensional experiences of Ugandan patients with HF over the course of their illness through diagnosis, treatment and dying?



# Study design

- Serial longitudinal qualitative in-depth interviews with HF patients admitted in General cardiology ward in MNRH
- Interviews scheduled: at first contact, 3 months and 6 months
- Monthly phone calls
- Earlier interviews if significant changes in patients' status

## Sampling and Recruitment

- Purposive sampling
- Inclusion criteria
- Advanced HF (Metra et al 2007)
- 18 years or older
- Consented to participate

# Sampling

- Exclusion
- Diminished cognitive capacity
- Severe Communication deficits
- Could not speak English or Luganda.

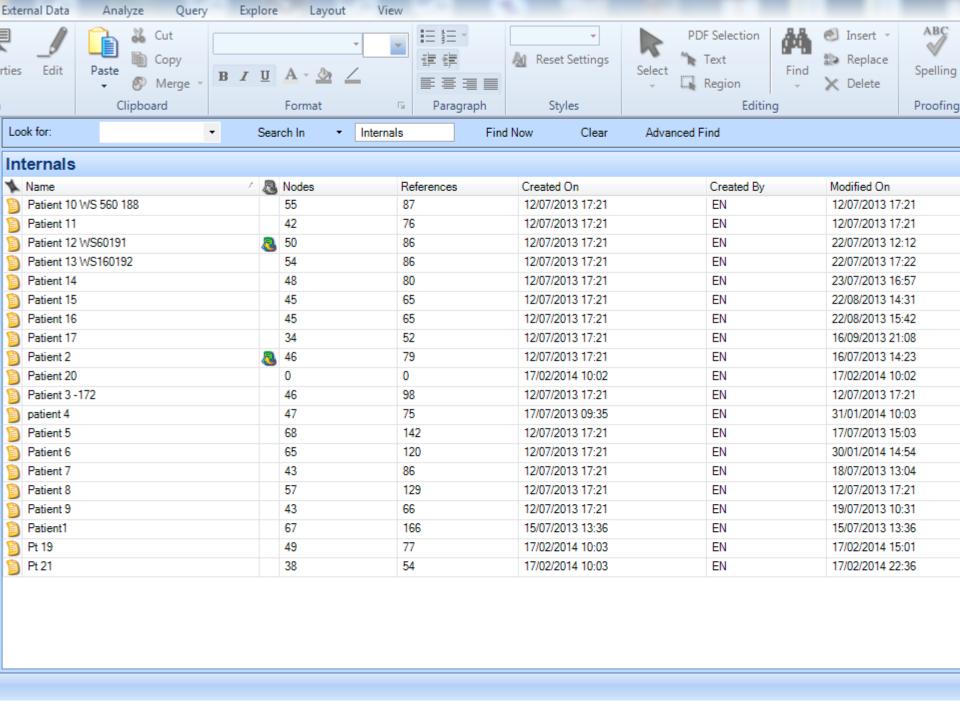
- Interview guide and recorded using digital voice recorder
- Field notes taken

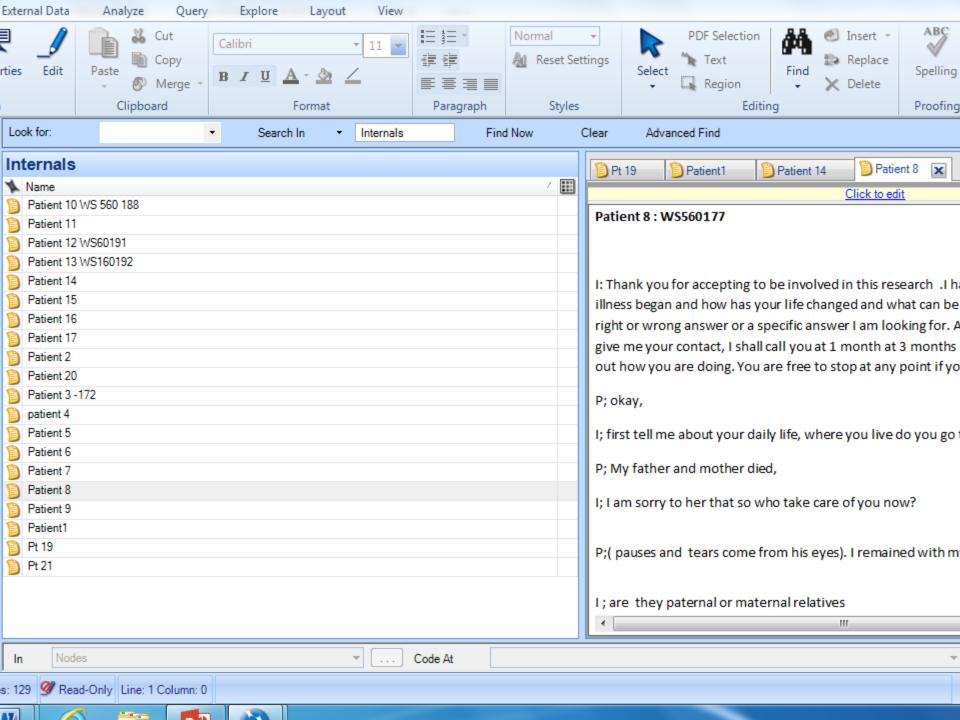
### **Ethics**

 Ethics Approval from UoE ethics committee, the Mulago Hospital Ethics Committee and the UNCST (Reference numbers: MREC: 313, D/GC/178, SS 3083).

# **Analysis**

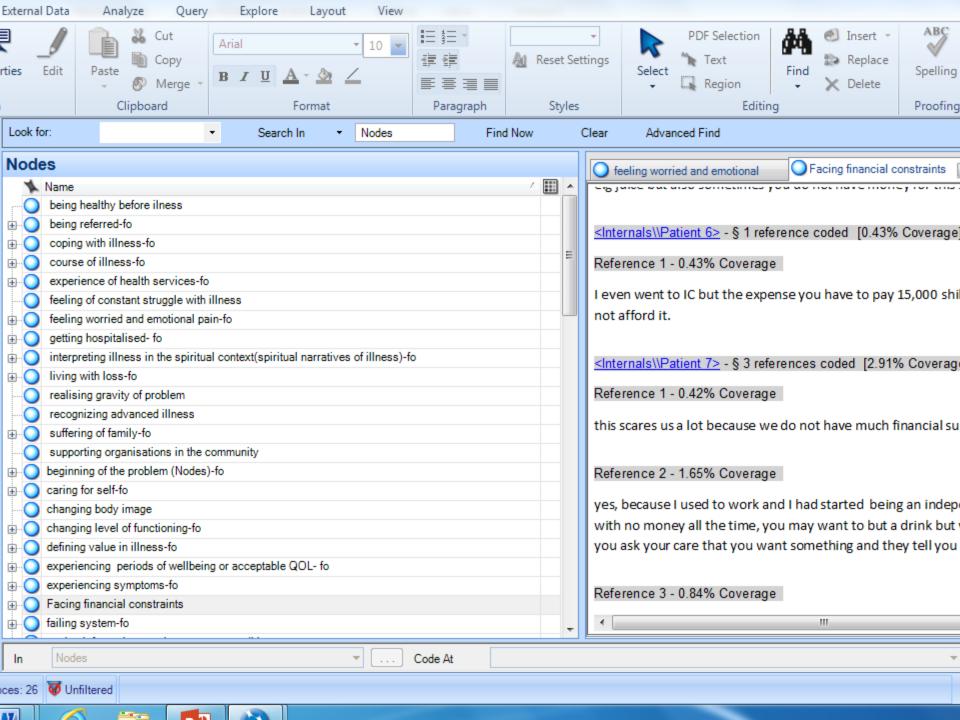
- Translated and transcribed
- Generation of data and analysis done concurrently
- A grounded theory approach :line by line, focused coding, theoretical coding and constant comparison.
- QSR Nvivo software 10 aided analysis





#### Nodes

Name	Source	s Refere	enc Created On	Created
having psychological needs	2	3	17/07/2013 14	EN
suffering	- 2	2	17/07/2013 14	EN
worrying about dying	2	2	16/07/2013 12	EN -
worrying about future	8	12	16/07/2013 14	EN
getting hospitalised- fo	1	1	30/01/2014 1	0 EN
O being hospitalised	12	20	15/07/2013 10	EN
interpreting illness in the spiritual context(spiritual narratives	13	17	15/07/2013 1	1 EN
explaining or understanding of illness in the spiritual di	4	7	16/07/2013 15	EN
alling God's test	1	1	18/07/2013 16	EN
O God's role	13	19	31/01/2014 15	EN
why not me	1	1	18/07/2013 11	EN
living with loss-fo	3	4	16/07/2013	11 EN
failing to care for family	2	2	17/07/2013 12	EN
O leaving school	1	2	23/07/2013 11	EN
O losing a job	2	3	22/07/2013 09	EN
losing ability to work	4	4	15/07/2013 11	EN
O losing control	1	2	22/07/2013 17	EN
O losing family resources	2	3	17/07/2013 13	EN
O losing income	4	5	15/07/2013 11	EN
O losing life dreams	2	6	17/07/2013 14	EN
loss of family relationships	1	1	16/09/2013 20	EN
wishing to continue school	2	2	16/07/2013 14	EN
realising gravity of problem	1	1	22/08/2013	15 EN
recognizing advanced illness	1	1	17/02/2014	15 EN
suffering of family-fo	1	1	17/07/2013	15 EN
being isolated from parent	1	1	17/02/2014 10	EN
O disrupting family plans	3	3	18/07/2013 15	EN
suffering family	4	4	22/07/2013 16	EN
supporting organisations in the community	1	1	17/02/2014	21 EN
O and the state of	2	4.0	30/01/2014	10 EN





## Results



- 48 interviews conducted
- (21-1<sup>st</sup>, 13-2<sup>nd</sup>, 6-3<sup>rd</sup>, 8 bereavement)
- 11 patients died by 6 months.



Characteristic	Total (%)	E UNIVERS
Age group		
18-20	1 (4.8%)	FOINBURG
21-30	7 (33.3%)	
31-40	3 (14.3%)	
41-50	3 (14.3%)	
51-60	6 (28.6%)	
61-70	1 (4.7%)	
Sex		
Female	15 (71.4%)	
<b>Education level</b>		
None	5 (23.8%)	
Primary	8 (38.1%)	
Secondary	7 (33.3%)	
Tertiary	1 (4.8%)	
Marital status		
Single	8 (38.1%)	
Married	6 (28.6%)	
Widowed or separated	7 (33.3%)	
Diagnosis		
Dilated cardiomyopathy	4 (19.0%)	
Endomyocardiofibrosis	2 (9.5%)	
Hypertensive heart disease	6 (28.7%)	
Rheumatic heart disease	7 (33.3%)	
HIV cardiomyopathy	2 (9.5%)	



## Living in the unknown



- 'I did not know what the problem was because I did not know how it felt to have heart disease' (patient 1 interview 1)
- 'Even in our community among friends, they ask what is the problem really? what do the doctors say? and you have nothing to say.'(Patient 5 interview 1)
- 'Most people in the village would tell me let us try our local herbs stop taking western medicine, I have my local healer who can help. Everyone had a herbalist they knew and different medicines. All this confused me. I started thinking should I leave this medicine and get herbal medicines? I did not know what to do, I was also waiting for a doctor to help me discern. But the problem is that the doctors do not give you information.' (Patient 8, Interview 1)

# Health illiteracy

### Delay in illness recognition

"I did not understand, initially I thought it is something that has come and will go because it would come and if I stood and rested it would then go away then I would start walking again, just like that". (Patient 8, Interview 1)

### Delay in seeking care

"I just went on with my duties as usual until I felt worse. It's when I could no longer work that I decided to go to hospital" (patient 3, interview 1)

# High reliance on local cultural and lay beliefs to make health decisions

'As you know in the village people thought I had been bewitched, I even tried and went to a witch doctor. He asked for 10,000 shillings and a chicken. I also took some herbs but I took them and did not get any change.' (Patient 13, Interview 1)

• 'The illness started with delivery of the child I have told you, I had problems with delivery, when the baby was turning in my womb he kicked my heart, I felt bad during the delivery I felt chest heaviness in labour.' (patient 17 interview 1)







## Health system challenges



### Lack of diagnostics

"They asked me for a chest X-ray but at Nnn but the machine there was out of function, so they referred me to another hospital.' (patient 5)

Inadequate skills in lower centers leading to delayed diagnosis

"I went to several clinics, but whenever they checked they failed to find what disease it was, until a year later' (patient 15)

#### Lack of medications

'We have to buy some medications, ever since I came to the hospital I had not got any dose, i had to buy the medicines but most times when we come to the clinic there are no medicines.' (Patient 5, Interview 1)

# High symptom burden and impaired function

'I used to feel easily tired on walking, when I lay flat I could not breathe well, I was coughing a lot I could not bend and was not able to do some work like chopping wood anymore. Then the abdomen started swelling and because of this I would not sleep. Now I cannot help myself, my mother cares for me I wake up and just sit, then sleep, I cannot even bend, I cannot not even bathe myself she bathes me.' (patient 14)



## Psychosocial impact of illness



### Anxiety

'I feel worried and sad sometimes, what really brings this is when I think of my children, because they are so young.' (Patient 5, Interview 1)

#### Facing rejection, stigma and isolation

'We do not relate well with neighbours because they think the illness will spread to them and catch them and yes even their children, they tell their children not to come near you.'

(patient 18 interview 1)



## Coping



#### Faith

'I read the Bible most of the time when I feel sad and discouraged I read the book of Job or Ezekiel, then I feel my heart is stronger and get more courage to live on and I say God you know everything and I surrender it to you.' (Patient 5, Interview 1)

### Strength in numbers

'What strengthens me is that when you come to hospital you find many others in the same condition and you think let me take courage, we are many, I am not in this alone it is not for one person.' (Patient 17, Interview 1)



## Spiritual impact of illness



- Spiritual distress
- 'For me I think God got tired of us, you feel of less value, you even reach the extent of admiring a crawling baby.' (Patient 4, Interview 1)

• 'So I said to God after all I have been through is this what You choose to pay me with? Is this the time You decide to give me this? You have seen wherever I have been.' (Patient 20, Interview 1)



## Conclusion



 This study identified similar findings in the HF illness experience to those in high income countries but also identified themes less common in the literature that could have led to a unique illness experience



## Acknowledgements



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