



- Elizabeth Namukwaya (MBChB, MMED internal medicine, PhD)
- Palliative care physician and Clinical head palliative care unit Mulago hospital
- Honorary senior lecturer Department of Medicine, Makerere College of health Sciences





EXPERIENCES OF PATIENTS LIVING WITH HEART FAILURE

Dr. Elizabeth Namukwaya



Background



- Need for multidisciplinary and palliative care involvement in advanced HF.
- Patients' experiences and wishes should inform care .
- Lack of information on patients' experiences 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 patient-centered palliative care for this increasingly prevalent group of patients.



AIM



- To understand the multidimensional experiences of Ugandan patients with HF along their disease trajectory.



Methodology



- 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
- Interview guide and recorded using digital voice recorder
- Field notes taken
- APCA African POS and POS-S
- Bereavement interviews with carers



Methodology



Inclusion criteria

- Advanced HF (Metra et al 2007)
- 18 years or older
- Consented to participate
- Home within 80km from Kampala

Exclusion

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



Ethics



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



Analysis



- A grounded theory approach used in analysis (line by line, focused coding, theoretical coding and constant comparison)
- QSR Nvivo software 10 aided analysis



Results



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



Results

Characteristic	Total (%)
Age group	
18-20	1 (4.8%)
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%)
Education level	
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%)



Significant Symptom experience and limited physical functioning



- *'In the beginning 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 it felt hot inside . 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)



Symptom	1 st interview N=21 Prevalence of symptom n (%)	1 st interview N=21 Prevalence of severe Symptoms (score ≥3) n (%)	2 nd interview N=13 Prevalence of symptom n(%)	2 nd interview N=13 Prevalence of severe Symptoms (score ≥3) n (%)	3 rd interview N=6 Prevalence of symptom n(%)	3 rd interview N=6 Prevalence of severe Symptoms (score ≥3) n(%)
Pain	17 (81)	11(52)	8(62)	8(62)	4 (71)	4(71)
Shortness of breath	21 (100)	20 (95)	10 (77)	9 (69)	6 (100)	3(50)
Fatigue	21 (100)	18 (86)	13 (100)	11(85)	6(100)	4(71)
Nausea and vomiting	18 (86)	4(19)	6 (46)	4 (31)	0(0)	0(0)
Anorexia	19(91)	13 (62)	10 (77)	10 (77)	3(50)	2(33)
Constipation	6 (29)	2 (10)	6 (46)	4 (31)	1 (16)	0 (0)
Mouth problems	11(52)	3 (14)	1 (8)	0 (0)	1(16)	1(16)
Drowsiness	8 (38)	6 (29)	6(46)	3(23)	1(16)	1(16)
Difficulty with mobility	21 (100)	17 (81)	12 (92)	10(77)	6 (100)	5(83)
Cough	13 (62)	11 (52)	7 (54)	6(46)	1(16)	1 (16)
Palpitations	5 (24)	5 (24)	3 (23)	3(23)	3 (50)	3 (50)
Oedema	19 (91)	17 (81)	6 (46)	6 (46)	3(33)	2 (33 %)

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, I felt chest pain, I could not carry things I used to carry I used to get something like difficulty in breathing I could no longer work, then I decided to go to hospital” (Patient 3, Interview 1)*



Lack of information on illness



- *‘They have done several scans but have not explained to us the results they did not explain to me the echo too because the person who explained only explained the first echo. I would like to know, what the problem is.’ (Patient 8, 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 not from a witch doctor but I got them from a herbalist, who told me that I had been bewitched 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.’ (patient5)*
- **Inadequate skills in lower centers leading to delayed diagnosis**
- *“I went to several clinics, wherever I went I was told to submit sputum so that they can look for the disease 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)*



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)
- **Poverty**
- *'I no longer work, but when I was working I was well off but since this illness started I stopped working ...If I only I can get food, I am starving because you see since morning I bought my daughter's child breakfast because I could not eat when the child had no food so I gave it to her and I just took tea, but I would like to eat but I have no money.'* (Patient 21, 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 put all strength and trust in God because I would not have managed on my own strength because there is a lot of pain in this illness. There at times when it comes and you think I am not going to see the next day but because you believe you find yourself alive the next day if it was not for that ahaa, there is a lot of pain.'* (Patient 20, Interview 1)
- *'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 pain**

- *‘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 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



Recommendations for practice and research



- Patients with HF are often missed by existing PC services. HF management should empower cardiology teams to do PC interventions and work with PC teams, with a focus on PC needs.
- Need to educate public about HF and to give patients information.
- More research is needed to determine when and how a palliative care approach in HF patients in Uganda should be initiated given the available resources





Acknowledgments

- Dr. Liz Grant, Prof.Scott Murray, Prof.Julia Downing, Dr.Mhoira Leng,
- MPCU team
- Study participants
- Staff cardiology ward Mulago hospital
- Ethics committees

