



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.
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- 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

Name	Nodes	References	Created On	Created By	Modified On
Patient 10 WS 560 188	55	87	12/07/2013 17:21	EN	12/07/2013 17:21
Patient 11	42	76	12/07/2013 17:21	EN	12/07/2013 17:21
Patient 12 WS60191	50	86	12/07/2013 17:21	EN	22/07/2013 12:12
Patient 13 WS160192	54	86	12/07/2013 17:21	EN	22/07/2013 17:22
Patient 14	48	80	12/07/2013 17:21	EN	23/07/2013 16:57
Patient 15	45	65	12/07/2013 17:21	EN	22/08/2013 14:31
Patient 16	45	65	12/07/2013 17:21	EN	22/08/2013 15:42
Patient 17	34	52	12/07/2013 17:21	EN	16/09/2013 21:08
Patient 2	46	79	12/07/2013 17:21	EN	16/07/2013 14:23
Patient 20	0	0	17/02/2014 10:02	EN	17/02/2014 10:02
Patient 3 -172	46	98	12/07/2013 17:21	EN	12/07/2013 17:21
patient 4	47	75	17/07/2013 09:35	EN	31/01/2014 10:03
Patient 5	68	142	12/07/2013 17:21	EN	17/07/2013 15:03
Patient 6	65	120	12/07/2013 17:21	EN	30/01/2014 14:54
Patient 7	43	86	12/07/2013 17:21	EN	18/07/2013 13:04
Patient 8	57	129	12/07/2013 17:21	EN	12/07/2013 17:21
Patient 9	43	66	12/07/2013 17:21	EN	19/07/2013 10:31
Patient1	67	166	15/07/2013 13:36	EN	15/07/2013 13:36
Pt 19	49	77	17/02/2014 10:03	EN	17/02/2014 15:01
Pt 21	38	54	17/02/2014 10:03	EN	17/02/2014 22:36

Line: 1 Column: 0

Nodes

Name	Sources	Referenc	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 10	EN
being hospitalised	12	20	15/07/2013 10	EN
interpreting illness in the spiritual context(spiritual narratives)	13	17	15/07/2013 11	EN
explaining or understanding of illness in the spiritual di	4	7	16/07/2013 15	EN
failing God's test	1	1	18/07/2013 16	EN
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
leaving school	1	2	23/07/2013 11	EN
losing a job	2	3	22/07/2013 09	EN
losing ability to work	4	4	15/07/2013 11	EN
losing control	1	2	22/07/2013 17	EN
losing family resources	2	3	17/07/2013 13	EN
losing income	4	5	15/07/2013 11	EN
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
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
supporting organisations in the community	2	4	30/01/2014 10	EN

External Data

Analyze

Query

Explore

Layout

View

Parties

Edit

Paste

Merge

Cut

Copy

Arial

10

B

I

U

A

Reset Settings

Select

Text

Region

PDF Selection

Find

Insert

Replace

Delete

Spelling

Proofing

Look for:

Search In

Nodes

Find Now

Clear

Advanced Find

Nodes

Name

being healthy before illness

being referred-fo

coping with illness-fo

course of illness-fo

experience of health services-fo

feeling of constant struggle with illness

feeling worried and emotional pain-fo

getting hospitalised- fo

interpreting illness in the spiritual context(spiritual narratives of illness)-fo

living with loss-fo

realising gravity of problem

recognizing advanced illness

suffering of family-fo

supporting organisations in the community

beginning of the problem (Nodes)-fo

caring for self-fo

changing body image

changing level of functioning-fo

defining value in illness-fo

experiencing periods of wellbeing or acceptable QOL- fo

experiencing symptoms-fo

Facing financial constraints

failing system-fo

feeling worried and emotional

Facing financial constraints

§ 1 reference coded [0.43% Coverage]

Reference 1 - 0.43% Coverage

I even went to IC but the expense you have to pay 15,000 shi
not afford it.

§ 3 references coded [2.91% Coverage]

Reference 1 - 0.42% Coverage

this scares us a lot because we do not have much financial su

Reference 2 - 1.65% Coverage

yes, because I used to work and I had started being an indepe
with no money all the time, you may want to but a drink but
you ask your care that you want something and they tell you

Reference 3 - 0.84% Coverage

In

Nodes

Code At

26

Unfiltered

Results

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

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%)

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)

- **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

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