



THE LIVED EXPERIENCE OF HEART FAILURE IN A LOWER / MIDDLE INCOME COUNTRY: PATIENT & CAREGIVER PERSPECTIVES

Joyette Aiken

Dr Steve Weaver

Dr Desmalee Holder-Nevins

Professor Nancy Edwards

Background

- Low and middle-income [and developing] countries, like Jamaica, bear the brunt of the heart failure disease burden;
 - resource constraints
 - lack of adequate infrastructure for diagnosis and treatment (Nunura et al., 2017)
- The effects extend to family and significant others as the patient's condition deteriorates (Clark, Spaling, & Harkness, 2014).
- Caregiving comes with a heavy physical, emotional and financial burden, which influences the level of support, and the quality of care given (Wingham, Frost, & Britten, 2017)

The Jamaican Context

- Aging population (Eldemire-Shearer et al., 2014)
- CVD is the leading cause of mortality in Jamaica (1:4)
 - **Hypertension & pre-hypertension (25.2% prevalence in 2008)**
 - **Diabetes (11.3% prevalence in adults 20-79, in 2015)**
 - Obesity, hypercholesteremia, smoking (Ferguson, et al. 2011).
- Afro-Caribbean patients with hypertension are likely to develop HF (Nunura et al., 2017)

Patient Perspectives:

- **Jeon et al., 2010: Living with HF**
- Systematic narrative review of 30 qualitative studies (1998-2008) describing the experience of living with chronic heart failure, mainly in the US and Sweden.
- Studies included were from adult populations in hospital, community and /or outpatient clinics.
- **Conclusions:**
- Patients:
 - Felt socially isolated
 - Lived in fear of losing control over their lives
 - Experienced negative effects of medications (especially diuretics)
 - Had ineffective coping
 - Eventual adjustment to changing situation

Lit Review: Caregiver Perspectives

- **Buck et al., 2015: Caregiver Contribution to HF patient self-care**
- Systematic review of 40 papers (qual and quan studies), published between 1948 and 2012 to examine the contribution of caregivers (CGs) to adult heart failure patients' self-care
- **Findings:**
- Caregiver support included:
 - implementing the prescribed plan of care
 - daily surveillance of symptoms, and weight
 - recognizing changes in the patient's condition
 - taking steps to intervene as necessary
- **Conclusion**
 - Informal caregivers played a major role in HF self-care, and contributed significantly to self-care maintenance, monitoring, and management of HF patients

Aim of Study

- To describe and interpret the issues that are important to patients with HF, and their caregivers
- To provide the evidence base for health care providers, and the nurse, specifically

Research Questions

◦ **How do Patients :**

- Describe the experience of living with HF?
- Perceive their own health and Quality of Life (QoL)
- Describe the barriers and/or facilitators to self-management of HF?
- Describe their social support?

◦ **How do Care givers:**

- Describe the experience of caring for a patient living with HF?
- Perceive their own health and QoL?
- Describe the barriers and/or facilitators to HF caregiving ?
- Describe their social support?

Methodology:

- Research Design:
 - Qualitative Study
 - **Phenomenological approach** – In depth interviews
- Understanding sought of the lived, and caregiving experience of heart failure from multiple patient-caregiver dyads.

Methodology

Setting

- UHWI: A 579 bed quasi-government regional tertiary institution.
- Cardiology Out-patient clinic

Study Population

12 patient-caregiver dyads were recruited.

Inclusion criteria:

Patient:

- Doctor diagnosed with symptomatic heart failure (NYHA II –IV)
- Attending Cardiology Clinic at UHWI
- Age >18 years, males & females
- Able to read and write English

Caregiver

- Identified by patient as the primary informal caregiver
- Adult
- Able to read and write English

Do you have heart failure?

OR

Do you take care of someone with heart failure?

We want to talk to YOU!

You may qualify to participate in a study which seeks to describe the lived experience of heart failure patients and caregivers who attend the Cardiology Clinic at the University Hospital of the West Indies.

CONTACT:
nurseledclinic@gmail.com
889-9079

- In-depth interviews lasting 45 – 60 minutes were done at the patients' homes
- 2 interviews were done per participant

Data collection

- Informed consent; researcher conducted interviews (Dec 2015 – Aug 2016)
- Interviews audio-taped
- Unstructured, open-ended interviews
 - Patients: “Please tell me what it is like to live with heart failure?”
 - Caregivers: “Please tell me what it is like to care for someone with heart failure?”
- Clarification sought with probes as necessary
- Field log and personal reflective journal maintained

Data Analysis: Moustakas' Method (1994)

- Tapes transcribed verbatim [**in patois**]
 - Transcripts anonymised
 - Text read repeatedly (content analysis)
 - Significant statements identified; grouped into emerging categories
- Manual coding.
- Reflective field notes added to the transcribed document.
- Concurrent coding and analysis continued until data saturation

Ethics

- Ethical approval from UHWI/UWI/FMS Ethics Committee.
- Institutional permission
- Respondents rights explained:
 - Consent
 - Confidentiality
- Provision for support services/referrals as necessary



RESULTS

1. PATIENT PERSPECTIVES
2. CAREGIVER PERSPECTIVES

11 Jamaican patient-caregiver dyads consented to participate in the study.

PATIENT (N=11)

- 5 males, 6 females
- Age range 40-80 years
- Mean age 61.5 years
- 6 were single; 3 were employed and had health insurance.
- All had multiple comorbidities
- Diagnosed with HF for between 6 months to 5 years.
- All were physician documented NYHA stage II-IV.

CAREGIVER (N=11)

- 8 females, 3 males
- Age range 31 - 74 years
- Mean age 49.6 years.
- All were first degree relatives of the patients
 - 4 female spouses; 3 male spouses
 - 3 daughters
 - 1 sibling
- 6 had full-time employment
- All caregivers lived in the same household with the care-recipient

Patient Perspectives

- Findings from the data collected from **patients** revolved around the following themes:
 - **Finding out** [about their heart failure],
 - **Now that I have heart failure.**
 - **Helping myself**
 - **Wanting to know**
 - **Finding strength through faith.**
 - **Dealing with the [healthcare] system,**
 - **Transitioning to new role**

Themes : PATIENT INTERVIEWS	Sub Themes
Finding Out	<ol style="list-style-type: none">1. Disbelief vs Acceptance2. Differentiating from pre-existing Comorbidities
Now that I have HF	<ol style="list-style-type: none">1. Internalizing the diagnosis2. Dealing with signs & symptoms3. Making time to reflect/ re-prioritize activities4. Boredom, social restriction/isolation5. Dealing with the side effects of polypharmacy6. Being mixed up and confused
Helping myself	<ol style="list-style-type: none">1. Adjusting diet and lifestyle2. Maintaining independence
Wanting to know	<ol style="list-style-type: none">1. How to manage2. Dealing with comorbidities

THEMES: PATIENT INTERVIEWS	SUB-THEMES cont'd
Dealing with the System	<ol style="list-style-type: none">1. Hospitalization2. Provider communication
Finding strength through Faith	<ol style="list-style-type: none">1. Importance of prayer2. Spiritual component to illness<ol style="list-style-type: none">a. Demon possessionb. Illness as payback
Transitioning to new role	<ol style="list-style-type: none">1. Accepting the sick role (role reversal)2. Dealing with sexual needs<ol style="list-style-type: none">a. Impotenceb. Rejectionc. Postponementd. Maintaining intimacye. Avoidance

Wanting to know:

- Patients wanted information about the condition:
 - how to manage comorbidities, signs and symptoms
- Dean looked up HF on the internet:
- ***“I used Google, cause I want to learn about this thing...a lot of it I don't understand, but I know it's not going away and I have to live with it.”***
- .

Transitioning to new role

- Relationships were affected the most with the role reversal and loss of independence.
 - ***” My daughter has me under house arrest...If I walk down the road she gets upset and says I must come back inside.”*** (Cliff)
- The role changes affected intimate relationships
 - Males experienced impotence or they avoided sexual activity altogether because of fear
 - Females responses varied from ardour (encouraging cuddling) to nonchalance

Dealing with the [health] system



- Patients felt that information regarding their own diagnosis was purposefully withheld:
 - ***“I asked the doctor how I have a heart condition and nobody said anything to me. He told me that the patient didn’t have to know everything”*** (Jean).
- There was fear and anxiety about what would happen during hospitalization, specifically admission to the CCU (coronary care unit) :
 - ***“I don’t want to go back there. CCU is a serious place... it mean that I’m in a bad serious condition...I don’t like it... it’s scary. Most nights I don’t sleep; I just watch for day light. Every time I sleep and wake up, somebody’s gone... I don’t like it...”***



CAREGIVER PERSPECTIVES

Caregiver Perspectives

- Findings from the data collected from **caregivers** revolved around the following themes:
 - **Becoming a caregiver**
 - **Tell me, please.**
 - **The stress of caring**

Themes : CAREGIVER INTERVIEWS

Sub-Themes & Caregiver Descriptors

Becoming a Caregiver

1. Gradual transition
2. Permanent upheaval
3. Role challenges
 - A. Watching
 - i. For complications/changes
 - ii. At night
 - iii. From a distance
4. Rewards
5. The Role of Intuition
 - A. Identifying worsening symptoms
 - B. Sensing distress

Tell me please

1. Risk factors for HF
2. How to manage at home
 - A. Internet/Google search
 - B. Observing nurses
3. Possible patient outcomes/ prognosis

THEMES: CAREGIVER INTERVIEWS

Sub-Themes & Caregiver Descriptors

The Stress of Caring

1. 24-hr commitment
 - A. Getting help
 - B. No time off
2. Physical stress
 - A. Lifting, moving
 - B. Assisting with ADLs
3. Emotional stress
 - A. Observing painful periods
 - B. **Communication/ relationships**
 - i. uncooperative patient
 - ii. Ungrateful patients
 - iii. Dealing with the Health Care Providers
 - a. Positive experience
 - b. Negative experience
 - C. Caring for the carer
4. Financial stress
 - A. Costs of care
 - i. Medication
 - a. Compliance vs Hospitalization
 - ii. Tests
 - iii. Transportation

Becoming a Caregiver

- Gradual transitioning into the caregiving role:
 - Accepting the responsibility; committing to learning all they could about the condition, what caused it, the prognosis, and how to manage it. They did whatever they needed to do, sometimes at great personal sacrifice
 - **“Well it’s my wife, and I try to do everything to help her.”** (Ben)
- Significant, and permanent upheaval :
 - **“This whole thing of mommy’s sickness changes everybody’s life. I need to be here 24/7 because she lives alone. I have to leave my [sick] husband alone at home.”** (Pet)

The caregiver experience of being watchful was very pervasive. They watched their loved ones eat, breathe, sleep.

- ***“I watch him at night...sometimes how he behaves in his sleep is frightening to me. Last week...he is sleeping, he’s breathing heavy, and stopped like for like a minute, and started again for a next 2 minutes. At times I just lie down there and watch him, no sleeping for me. Those things are scary- he’s struggling in his sleep to breathe. Sometimes I can hear him actually wheeze” (Vonnie).***

Watching...

Tell me , please

- None of the caregivers had had any prior training how to deal with HF, but they drew on past experiences *and their common sense*
 - ***“Nobody taught me...you just use common sense on top of what you know.”***(Ann)
- They asked questions, observed what the nurses did during hospitalization, did Google searches, and watched TV to get the information they needed.
- ***” I watch a lot of TV, Like ‘House’ and stuff like that. I learn a lot from it”***(Trish).

The Stress of Caring

- As care dependence increased it was especially challenging for caregivers who had to enforce activity restrictions, and medication administration. They experienced uncooperative and sometimes resentful responses from clients:
- ***“..It’s difficult sometimes cause he doesn’t listen. Sometimes he shouts at me and the neighbours say: “Look at that, how you care for him and he doesn’t appreciate it!” (May).***

Communication with HCP

- Caregivers wanted more information from health care providers about how to manage HF at home. Concerns related to possible patient outcomes/ prognosis were never addressed.
 - **“...nobody tells me anything. I am not sure what to expect or how to respond. Mainly I am scared and anxious about this. I am very worried.”** (Ann)
- They were always wondering if the next period of acute illness would be “the one”. This anticipation created a lot of fear and anxiety. May reminisced about one incident when her husband became acutely ill at home and was hospitalized:
 - **“ I was sure he was going to die ...I thought he wouldn't make it and I tried to prepare myself, but he did!”**. (May)
- They felt powerless but developed their own philosophical and pragmatic responses to cope with the situation, which eventually took a toll on their own well-being

Summary Findings

Patients

- **How do Patients :**
 - Describe the experience of living with HF?
 - **Wicked**
 - Perceive their own health and Quality of Life (QoL)
 - **Trying to cope, living within the limits & finding strength through faith**
 - Describe the barriers and/or facilitators to self-management of HF?
 - **Want to know more**
 - Describe their social support?
 - **Respectful care**

Caregivers

- **How do Caregivers :**
 - Describe the caregiving experience of HF?
 - **Stressful**
 - Perceive their own health and Quality of Life (QoL)
 - **Little concern for themselves**
 - Describe the barriers and/or facilitators to self-management of HF?
 - **Improved communication**
 - Describe their social support?
 - **Help wanted**

Recommendations

- Health care providers have responsibility for assessing health literacy levels and providing information in a manner that will result in patient & caregiver engagement (Adams, 2010).
- Nurses have to be **INTENTIONAL** with patient & family education at every interaction
- A **patient-centred approach to care** and facilitating a **shared decision-making care environment** may help to ameliorate the issues resulting from uncertainty and the tensions arising from the need to know, in patients and their caregivers

Limitations of this study

- Patients identified me as a nurse based on the cardiologists' introduction of me as a nurse doing research at recruitment.
- This perception of the participants might have [positively] impacted the freedom with which they interacted (? bias). Men spoke un-inhibitedly, and initiated the concern about their sexual needs without any prompting. On the other hand, they were always asking questions and seeking advice about concerns they had forcing me into clinician role instead of independent researcher. They also referred to me as Nurse.
- No available data on HF in the Jamaican context for comparison
- Participation in the study was limited to patients in the cardiology clinic at the UHWI

- Participants & Caregivers from the UHWI Cardiology Clinic
- Cardiologists & Nurses in the Cardiology Clinic at the UHWI
- Research Supervisors : Dr Weaver, Dr Holder-Nevins & Prof Nancy Edwards (Ret'd)
- Colleagues at UWISON , Mona & WJC





Family walked with me.....

Last but not least : Thank GOD, for strength....



References

- Adams, R.J. (2010). Improving health outcomes with better patient understanding and education. *Risk Management and Healthcare Policy*, 3, 61–72
- Buck, H., Harkness, K., Wion, R., Carroll, S., Cosman, T., Kaasalainen, S., ..., & Arthur, H. (2015). Caregivers' contributions to heart failure self-care: A systematic review. *European Journal of Cardiovascular Nursing*, 14(1) 79 –89. DOI: 10.1177/1474515113518434
- Clark, A.M., Spaling, M., Harkness K. (2013). Determinants of effective heart failure self-care: a systematic review of patients' and caregivers' perceptions. *Heart*, 100, 716–721
- Eldemire -Shearer, D., Mitchell- Fearon, K., Lawes, H., Waldron, N., James, K., & Holder-Nevins, D. (2014). Ageing of Jamaica's population - What are the implications for healthcare?. *West Indian med. j.* [online]. 2014, vol.63, n.1, pp. 3-8. ISSN 0043-3144.
- Ferguson, T., Francis, D., Tulloch-Reid, M., Younger, N., McFarlane, S., & Wilks, R. (2011). An update on the burden of cardiovascular disease risk factors in Jamaica: Findings from the Jamaica Health and Lifestyle Survey 2007-2008. *West Indian Med. J.* [online]. 60: 4. 422-428. ISSN 0043-3144.
- Jeon, Y., Kraus, S., Jowsey, T., & Glasgow, N. (2010). The experience of living with chronic heart failure: A narrative review of qualitative studies. *BMC Health Services Research*, 10:77. doi:10.1186/1472-6963-10-77
- Nunura, F., Tulloch-Reid, E., Brooks, J., Baugh, D., & Madu, E. (2017). Heart failure demographic and clinical Features: The Caribbean perspective: A single-center 100-case series discussion and review of the literature. DOI: 10.26717/BJSTR.2017.01.000332
- Wingham J, Frost J, Britten N. Behind the smile: qualitative study of caregivers' anguish and management responses while caring for someone living with heart failure. *BMJ Open*;7:e014126. doi:10.1136/ bmjopen-2016-014126