45th Biennial Convention (16-20 November 2019)

The Lived Experience of Heart Failure in a Lower Middle-Income Country: Patient and Caregiver Perspectives

Joyette L. Aiken, MScN (Ed)[1]
Steve R. Weaver, PhD[1]
Desmalee Holder-Nevins, PhD[2]
Nancy Edwards, PhD[3]
(1)The UWI School of Nursing, Mona, The University of the West Indies, St Andrew, Jamaica
(2)Department of Community Health and Psychiatry, The University of the West Indies, St Andrew, Jamaica
(3)School of Nursing, University of Ottawa, University of Ottawa, Ottawa, ON, Canada

Heart failure is a growing problem in Jamaica, and patients rely on informal caregiving support to help them manage the condition as the disease progresses. A diagnosis of heart failure has far-reaching effects on patients and their families, as heart failure will gradually progress from relative stability, to the point where there is a pattern of acute exacerbations resulting in multiple hospitalizations, periods of recovery, and eventual demise.

This hermeneutic/interpretive phenomenological study gave insights as to how 11 Jamaican patients – caregiver dyads experienced and coped with heart failure. Patients were purposively selected, and their caregivers were invited to participate as well. Following informed consent, in-depth, unstructured interviews were held at the patients' home, which afforded the privacy necessary to conduct the interview. All interviews were conducted by the researcher and tape recorded. Patient and caregiver interview transcripts were analysed from verbatim narrative which was mainly in Jamaican patois. A multi-stage data analysis, using Moustakas' method, was done manually. The patients and their informal caregivers were all Jamaicans, and first-degree relatives, and who lived in the same households (spouses, daughters, and sibling).
Patients were mainly females (55%) with a mean age of 62 years. Seven themes were derived from patient interviews: Finding out; Now that I have heart failure; Helping myself; Wanting to know; Dealing with the system; Finding strength through (religious) faith; and Role changes. Caregivers were mainly females (73%) with a mean age of 49.6 years. Three themes were derived from caregiver interviews: Becoming a caregiver; Tell me, please; and The stress of caring.
Both patients and their caregivers wanted to know how to manage, not only the disease process, but also their individual roles, and the relationship issues that emerged. Caregivers had no role preparation and relied on intuition because they lacked the information necessary for decision making. Intersecting themes reveal a significant gap in patient /caregiver knowledge that could negatively impact patient outcomes. Study findings provide a baseline for tailored interventions to improve knowledge levels and eventual outcomes for patients with heart failure, and their caregivers, in a LMIC.

Title:

The Lived Experience of Heart Failure in a Lower Middle-Income Country: Patient and Caregiver Perspectives

Keywords:

Caregivers, Heart failure and Lived experience

References:

Bowry, A.D., Lewey, J., Dugani, S.B., & Choudhry, N.K. (2015). The burden of cardiovascular disease in low-and middle -income countries: Epidemiology and management. *Can Journal of Cardiology*.31(9)1151-9. Doi: 10.1016/j.cjca.2015.06.028.

Browne, S., McDonald, S., May, C., McLeod, U., & Mair, F. (20 14). Patient, carer and professional perspectives on barriers and facilitators to quality care in advanced heart failure. *PLoS One*, 9(3), e93288.

Buck, H.G., Harkness,K., Wion, R., Carroll, S., Cosman, T., Kassalainen, S.,…Arthur, H.M. (2014). *European Journal of Cardiovascular Nursing*, 20(10) 1 –11. DOI: 10.1177/1474515113518434.

Fry, M., McLachlan, S., Purdy, S., Sanders, T., Kadam, U., & Chew-Graham, C. (2016). The implications of living with heart failure; the impact on everyday life, family support, co-morbidities and access to healthcare: A secondary qualitative analysis. *BMC Family Practice*. https://doi.org/10.1186/s12875-016-0537-5.

Go, A., Mozaffarian, D., Roger, V., Benjamin, E., Berry, J., Blaha, M…… Turner, M. (2014). Executive summary: Heart disease and stroke statistics--2014 update: A report from the American Heart Association. *Circulation*, 129(3):399-410. doi: 10.1161/01.cir.0000442015.53336.12.

Moustakas, C. (1994). *Phenomenological Research Methods*. Thousand Oaks, CA: Sage Publications.

National Alliance for Caregiving and AARP Public Policy Institute. (2015). Caregiving in the US:2015. Retrieved from https://www.caregiving.org/caregiving2015

Toukhsati, S.R., & Hare, D.L. (2016). Towards optimal heart failure care: Couples-oriented strategies to improve patient adherence and health outcomes. *Current Cardiology Reviews*,12, 243-248. doi: 10.2174/1573403X126661606061 22451.

Van Manen M. (1990). *Researching lived experience: Human science for an action sensitive pedagogy.* London, Ontario: Althouse.

Wingham, J., Frost, J., Britten, N., Jolly, K., Greaves, C., Abraham, C., & Dalal, H. (2015). Needs of caregivers in heart failure management: A qualitative study. *Chronic Illness*, 11(4) 304–319. DOI: 10.1177/1742395315574765.

Abstract Summary:

The experience of heart failure management and self-care in the resource limited context of a LMIC may be very different from the first world experience, and could have implications for morbidity, mortality and quality of life in the affected patient-caregiver dyads. This study addresses that gap in the literature.

Content Outline:

Introduction

Significant advances have been made in the management of heart failure; however, it is now considered a growing public health concern worldwide, affecting about 1-5% of the general population and about 20 - 25% of those over 80 years old (Go et al., 2014). Lower and middle-income countries (LMIC), like Jamaica, bear the brunt of the cardiovascular disease burden (Bowry, Lewey, Dugani, & Choudhry, 2015).

Body

The physiological limitations with the activities of daily living, and the psycho-social and economic impact of heart failure on the patient and his family may be extensive (Fry et al., 2016). The issues related to the lived experience, as well as care of patients with heart failure, are very complex and overall, quality of life and functionality are affected (Fry et al., 2016). As the disease progresses, patients become increasingly dependent on informal caregivers as a mainstay of ensuring optimal day to day management. Informal caregivers are those persons such as family and friends who care for the patient without remuneration and they usually are without formal training (National Alliance for Caregiving and AARP Public Policy Institute, 2015). The bulk of these informal caregivers are family members who spend an average of four years working over 20 hours weekly caring for their loved ones (National Alliance for Caregiving and AARP Public Policy Institute, 2015). Informal caregivers play a major role in heart failure self-care, contributing significantly to self-care maintenance, monitoring, and management (Buck et al, 2015). The effective physical, psychological and social support given by the caregivers have been shown to improve patient outcomes and quality of life for patients suffering with heart failure (Buck et al., 2015). However, informal caregiving may be a burden physically, psychologically as well as financially, without the requisite support (Browne, McDonald, May, McLeod, & Mair, 2014)

The research questions focussed on the lived experiences of both the patients and their caregivers: How do patients describe the experience of living with heart failure? How do caregivers describe the experience of caring for a patient living with heart failure? Are there intersecting dyad experiences?

Hermeneutic /interpretive phenomenology was chosen as the underpinning approach for this qualitative study as the researcher sought understanding of the lived, and caregiving experience of heart failure from multiple patient-caregiver dyads in their individual contexts. The direct description of the phenomena as experienced by the ‘insiders’ is the objective of phenomenology, without theories, or offering causal explanations of their objective reality (Van Manen, 1990). The meaning/interpretation of patient and caregiver experiences was constructed from their individual and inter-connected realities.

Adult heart failure patients registered in the Cardiology clinic of the study hospital, and their primary informal caregivers (identified by the patients as the person who took care of them at home, without payment) were purposively recruited, having met the inclusion criteria. Male and female adult patients who were currently attending the UHWI cardiology clinic and had a documented doctor diagnosis of symptomatic heart failure (NYHA II –IV) were invited to participate in the study. Participants were required to be able to read and write English. Caregivers had to be over age 18 years, and receive no payment for services rendered. The participants were invited to take part in an open-ended interview to discuss the effect heart failure had on their everyday lives.
Following informed consent, in-depth, unstructured interviews lasting approximately 45-60 minutes each, were held at the patients' home. All interviews were conducted by the researcher and tape recorded. One key question was asked of all patients, "Please tell me what it is like to live with heart failure?" and another of all caregivers, "Please tell me what it is like to care for someone with heart failure?" The participants were free to lead the interview and express themselves in as much detail as they wished, providing the full context of living with heart failure, or caring for someone with heart failure. Clarification was sought with probes, as necessary. A minimum of two interviews were done per participant. A field log with reflective notes, and a personal journal were used to record observations, and the researchers' feelings and perceptions throughout the research process.
The tape-recorded interviews were transcribed verbatim. The participant responses were mainly in Jamaican patois, and this was retained as the source language. Moustakas' (1994) method for phenomenological analysis was used to analyse data. This method involved line-by-line analysis of the transcribed interviews, and coding data into relevant sentences and phrases after listening to the interviews during transcription and re-reading the transcripts multiple times. The reflective field notes, were added to the individually transcribed documents. For each transcript, concurrent coding and analysis continued until additional unique categories were no longer identified. Caregiver and patient transcripts were all anonymized; and analysed manually. Statements across all patients, with similar meanings, were grouped together in a constant comparative analysis as the researcher examined the data for metaphors and similes and other uses of the language that could indicate an important theme/concept. Major commonalities were identified as themes/subthemes, and differences (comparisons and contrasts) identified. Texts with similar meanings, across scripts, were grouped together to form preliminary codes. Core concepts across these codes were identified and grouped together to form larger codes. A similar procedure was carried out with the caregiver transcripts in this multi-stage analysis.
In the final stage of analysis, the patient and caregiver experiences were distilled as the researcher described "what" participants experienced using verbatim examples; and the "how" (setting and context). Emerging from that comprehensive analysis was the identification of the 'essence' of the lived experience of heart failure, which was comprehensively described. A thick, rich description using the meanings distilled from the participants' words, was used to convey the lived experience, and the caregiving experience, and the intersecting experiences of both patient and caregiver were outlined.

Ethical and institutional approval were received for this study, and participants were advised of their rights as study participants. Pseudonyms were used to describe the lived experiences.

Eleven patient-caregiver dyads participated in the study. Data were collected December 2015 to August 2016. Of the 5 males and 6 female patients, all had multiple comorbidities, had been diagnosed with heart failure for between six months to five years, and were physician documented NYHA stage II - III.

Caregivers were between 31 and 74 years. All were first degree relatives of the patients and lived in the same household with the care recipient. Eight caregivers were female (5 spouses, 2 daughters, 1 sister). The three male caregivers were spouses. Six caregivers had full-time employment.

For the lived experience of patients, seven themes were derived, which revolved around patients finding out about their heart failure, and the changes they had had to make with the limitations imposed by their symptoms. They described how all aspects of their lives were affected, and the need to find ways to cope. Most found strength through their faith. Dealing with the healthcare system and maintaining their social and intimate relationships were sometimes problematic.

Patients described how having heart failure changed their lives. Jean, NYHA III explained:

"*I have to have someone to help to put me on the bed. I cannot help myself, I can only kotch up on 3 pillows in the night to get a little rest. It's very rough*."

The three themes that were uncovered from the caregiver interviews were: Becoming a Caregiver; Tell Me, Please; and The Stress of Caring. The themes suggested that participants transitioned to the role with little preparation, and for most, it was a period of uncertainty. Many relied on their intuition because they lacked the information necessary for good decision making. Caregivers took their responsibilities seriously, enforcing limitations. Caregiving was a 24-hour-a-day, stressful job; they spent many hours just watching, and waiting, not knowing quite what to expect. The caregiver experience of being watchful was very pervasive. They 'watched' their loved ones eat, breathe, sleep. It's what they did… they watched. They felt accountable for every minute, every action. Vonnie gave her experience of watching*:*

"I watch him at night…it is frightening to me. Last week while he was sleeping, he was breathing heavy, and he stopped like for a minute and start again for a next 2 minutes. I just lie down there and watch him, no sleeping (for me). Them things are scary- him struggling in his sleep to breathe. Sometimes I can hear him actually wheeze".

The costs of providing care were also a concern. They described neglecting their own personal well-being to prioritize the needs of their care-recipients and they took an advocacy role during health-care provider interactions on behalf of the relative they cared for.

Intersecting themes from the experience of both the patients and the caregivers showed that both had to deal with uncertainty of heart failure and learn how to manage the condition; adapt to new roles, and finally embrace a 'new normal'. Living with and caring for someone living with heart failure was challenging. In several instances there were some important similarities and differences in the perspectives of patients and caregivers which encapsulated the lived experience, and the caregiving experience of heart failure. Ultimately, the experiences reflected the pressure of uncertainty of

knowing “how” and “why” of the heart failure diagnosis and management, which resulted in tensions between patient and caregiver. If the uncertainty remains unaddressed by the health care provider, and the information needs are not met, it could result in disengagement and some resentment to care, as shown in this study.

As new roles were transitioned into, both patients and caregivers settled into new rhythms of function that were very dynamic. The meanings ascribed to the lived experience of living with and caring for a person with heart failure concurs with the literature in the description of coping with distressing symptoms, role reversals, limited psychological and material support, all of which invariably lead to a decreased quality of life (Wingham, et al., 2013).

Caregivers persist in their commitment despite the significant stress they face, very few resources or social or technical support. Patients continue to find ways to cope within the limitations imposed by heart failure and are motivated to help themselves.

Conclusion

Health care providers have a responsibility to help patients and caregivers understand heart failure and its sequelae, and thereby increase their self-efficacy and possibly their quality of life (Toukhsati, Driscoll & Hare, 2015). Based on the findings of this study, we conclude that there is a need for improved levels of health care provider communication to both patients and their caregivers. The intersecting themes reveal a significant gap in patient /caregiver knowledge that could negatively impact patient outcomes. Study findings provide a baseline for tailored interventions to improve knowledge levels and eventual outcomes for patients with heart failure, and their caregivers, in a LMIC.

First Primary Presenting Author

Primary Presenting Author

Joyette L. Aiken, MScN (Ed)
The University of the West Indies
The UWI School of Nursing, Mona
Lecturer
St Andrew
Jamaica

Author Summary: Joyette Aiken has been a nurse educator for the last 12 years, teaching Medical-Surgical and Specialized nursing care to undergraduate students. Currently she is a PhD student researching issues related heart failure in patient-caregiver dyads across the Caribbean. She has presented at several local and international fora. Her research interests include Lateral violence in Nursing, and Health literacy.

Second Author

Steve R. Weaver, PhD
The University of the West Indies
The UWI School of Nursing, Mona
Head of School
Mona Campus

St Andrew
Jamaica

Author Summary: He is the primary research supervisor, and an author of this study. He has significant expertise in qualitative research and has served as teacher, supervisor and mentor to many graduate students in his department.

Third Author

Desmalee Holder-Nevins, PhD
The University of the West Indies
Department of Community Health and Psychiatry
Senior Lecturer
Mona Campus
St Andrew
Jamaica

Author Summary: Dr Holder-Nevins has many years experience as a qualitative researcher. She has a special interest in issues related to popular music and its impact on health promotion in adolescents.

Fourth Author

Nancy Edwards, PhD
University of Ottawa
School of Nursing, University of Ottawa
Professor Emeritus
Ottawa Ontario
Canada

Author Summary: Professor Edwards is mentor to many graduate students Sub-Saharan Africa and the Caribbean. Her leadership and research has been recognised internationally, and in Canada with numerous awards and accolades.