# **ORIGINAL ARTICLE**

# Bahraini men living with heart failure: A phenomenological study

Shereen Mohamed Mohamed\*, Catherine S. O'Neill Salmaneya Medical complex, Ministry of Health, Bahrain

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#### **ABSTRACT**

**Background:** Heart failure (HF) is a worldwide chronic and progressive condition. HF symptoms affect an individual's life perspectives, and create dramatic changes in their everyday living routines. Qualitative studies showed that HF symptoms were associated with reported low quality of life, reduced physical activities, and altered social interactions and relationships. The aim of this study was to explore the experiences of men under the age of 65 diagnosed with HF living in the Kingdom of Bahrain. **Methods:** An interpretive phenomenological approach was used. In-depth, semi-structured interviews were conducted with six men under the age of 65 who were diagnosed with HF for a period of not less than a year. The interviews were conducted in Arabic, and then translated and transcribed into English. Smith's framework was drawn on for data analysis.

Results: Three main themes emerged: the physical burden of the illness; the psychosocial aspects of the illness and living with HF. The findings showed that the physical symptoms shaped men's everyday work activities and also their resting and sleeping patterns. Participants expressed feelings of frustration, anger, and sadness following the diagnosis and recounted how their masculinity roles changed at home and in society. Families played a major role giving support to the men, who utilized different coping strategies, as lifestyle and behavioral modifications were adopted. Keeping faith and a belief in God, coupled with social support was a thread that connected all participants coping strategies. The authors recommend that educational programs for men who are diagnosed with HF and their families would help them cope with this chronic illness.

**Conclusions:** Heart failure patients experience dramatic changes in their life. An understanding of the challenges they are facing in their daily living enables them, and those who care for them, both families and nurses, to creatively assist them live with the difficulties encountered with HF.

Key Words: Heart failure, Phenomenology, Masculinity, Social support

#### 1. Introduction

Heart failure (HF) is considered a global epidemic worldwide and a major cause of morbidity and mortality. Approximately 5,700,000 Americans are diagnosed with HF annually and by the year 2030 it is expected that HF will affect approximately 10% of the US population over the age of 65 years. [1] The health needs of people suffering from HF are poorly understood, and despite intense medical therapy for symptom relief, patients continue to suffer from progressive symptoms,

hospitalizations and high rates of mortality.<sup>[2]</sup> HF patients experience physical limitations, poor psychological health and in some instances cognitive decline; all of which affects their ability to interact socially and resulting in poor quality of life.<sup>[3]</sup> Studies have indicated that for HF patients' physical and mental wellness formed the basis of quality of life and were significantly linked to the prognosis and outcomes of HF.<sup>[4,5]</sup> Physical symptoms resulted in a number of limitations affecting the patient's daily activities. For example,

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<sup>\*</sup>Correspondence: Shereen Mohamed Mohamed; Email: she-82@hotmail.com; Address: Salmaneya Medical complex, Ministry of Health, Bahrain.

difficulties in climbing the stairs, doing household chores, carrying items, expressing sexuality and other activities of daily living were restricted.<sup>[6]</sup>

It also seemed that gender and age played a significant role in how patients' experience living with HF.<sup>[7]</sup> Recognizing gender and age differences is crucial when health care professionals are offering advice and planning care as the biophysiological and psychological status differences between men and women determines and shapes their experiences and abilities to successfully manage daily living activities. Gender in particular shapes health behaviors. In the case of men presenting with HF their masculinity that is generally defined as the common understanding of the meaning of being a man, in how to behave, how to present oneself, and so forth, is influenced by the sociocultural context that defines masculinity.[8-11] The manner in which men engaged with heath care systems was shaped by their masculinity and also shaped their decision-making processes relating to the use of health services. [8,9] Other studies revealed that the negative effects of symptoms, depression and anxiety, resulted in low self-worth and feelings of guilt.[12] It also seemed that some men experienced changed identities following diagnosis and they attempted to reshape and rebuild their sense of self and social identities by engaging in various social activities.<sup>[13]</sup> Insufficient information about the disease led to poor outcomes, anxiety, frustration, unrealistic expectations and ambiguity about the future. The personal relationships of both men and women were also affected by a diagnosis of HF resulting in changed family roles and relationships with others. All of which affected the individual's self care and management of the disease.[14]

There are no specific statistics relating directly to the prevalence of HF in the Arab Gulf states or in Bahrain. Yet, according to Bahrain Ministry of Health, [15] a country with a population of approximately 1.2 million, of which 584,688,00 are Bahraini, males number 295,878.00. [16] The estimated total number of patients admitted with hypertensive heart disease in the year 2011 was around 486 male patients and 447 females. Of these 233 males were under the age of 65, with 110 females. In addition, 47 males were admitted with pulmonary oedema, and 39 females under the age of 65 years. Thus, statistically the number of men admitted with hypertensive diseases and pulmonary oedema was higher than females in the age category of 45-64 years, an age that is considered the average retirement age according to Bahrain's social insurance system. [17]

Bahrain, one of the countries comprising the Arab Gulf States, has experienced an increase in the HF cases despite improved access to health care and the use of medical technology. Bahrain's society similar to other developed countries

has become increasingly urbanized, resulting in decreased physical activity, presenting the possibility that cardiovascular disease may in the future become a major cause of morbidity and mortality. Thus, the need for planned management of HF based on scientific clinical evidence is necessary as presently there is no cure for the disease. Symptom management and improvement of the quality of life of patients should, however, be considered key elements of all treatment plans and educational programs for patients and their caregivers to ensure high levels of positive patient outcomes. [19]

Given the first author's observations of the impact of HF on patients on a daily basis, the burden of symptoms, readmissions and the difficulties that patients and families experience following a diagnosis of HF, the author set out to explore the experiences of men younger than 65 years diagnosed and living with HF in Bahrain.

The objectives of the study were to: (1) To explore the patients' lived experience with HF; (2) To describe the effects of HF on the patients' life style and activities; and (3) To identify supports that may be necessary to help them live better with HF. The research question below was developed to answer the above aim and objectives: "What are the experiences of men under the age of 65 living with HF in Bahrain?"

# 2. METHODOLOGY

A phenomenological study was the research design used to explore the lived experiences of men living with HF. Phenomenology is the perfect path for the purpose of studying the lived experience of a given phenomenon, as it facilitates the researcher in exploring the phenomenon under study and gives the researcher rich ideas in how to study and comprehend living experiences.<sup>[20]</sup> This is achieved by the researcher gaining an understanding of the phenomenon from the participants' own words, and perspectives, all of which are grounded in the context of the situation.<sup>[21]</sup> In nursing. the use of phenomenological studies have become an important qualitative approach and the knowledge of the lived experience is valuable for nurses so that they have a better understanding of "what it is like to be" when patients are ill.<sup>[22]</sup> This type of information and understanding will hopefully assist nurses in providing sensitive ethical based care. In addition, knowledge of the lived experiences of patients is important to develop nurse education so that knowledge of the patient's personal world will help nurses give care that is patient-centered and evidence-based.[22]

Nurse researchers have duel duties. Firstly they are asked to explore known knowledge and secondly to gain insights from the experiences of participants in order to improve the

nursing practice. Nurses are uniquely placed to be involved in phenomenological studies, as the nurse is the person who is generally closely involved in individuals and families' experiences. Nurses witnesses and co-participate in patient experiences and when they are ethically moved to document these experiences they can produce research that can enhance practice. [23]

#### 2.1 Ethical considerations

Ethical approval to carry out the study was initially obtained from the institutional ethics committee (REC). This was followed by ethical approval from the teaching hospital in which the research was carried out. Following ethical approval a letter was sent to the nursing administration of the hospital to obtain permission and cooperation from the staff in the unit. Following the above procedures, patients who were already part of another study under the auspices of cardiac physicians, [24] were with the approval of the physicians, approached and invited to be part of this study. An information sheet was provided to participants who were in-patients. For outpatients information was initially given by phone and this was followed up with a written information sheet. Witten consent was obtained from all participants prior to interview. The data was stored in the researcher's personal computer, and password protected. All records were deleted from the original recorder immediately after the transfer. The records and study papers were destroyed when the study was completed.

# 2.2 Population, sample and sampling

The population in this study were male patients under the age of 65 diagnosed with HF who were being treated in a large teaching hospital in Bahrain. Six participants were purposefully recruited for the study. Initially, it was proposed to include eight to ten participants, but while generating the data (interviewing) the researcher in consultation with the second author, observed from the data that no new information or patterns were emerging, thus, a decision was made to conclude data generation following six interviews. Initially, the authors decided to recruit participants only from the outpatients department, as based on the first authors clinical experience patients attending outpatient were in a more stable medical condition.

The response rate was poor. Reasons given by outpatients for non-participation were fatigue and the difficulties of getting to the hospital for interview. Thus, the authors decided to recruit participants from both outpatients and inpatients who were in a stable medical condition and who were willing to be a part of the study.

In Bahrain men generally adopt traditional roles of "bread

winner" and are the main family supporters financially. Thus, their illness has more impact on the family, financially than if a female is diagnosed as an HF patient. Similarly to other chronic illnesses HF induces feelings of pain, tiredness, and strength reduction all of which detract from a man's independence and authority all attributes associated with the masculinity and gender roles.<sup>[9]</sup> Accordingly, men under the age of 65 years were recruited as they are considered socially and financially responsible, and the official retirement age in Bahrain is 65 years.<sup>[17]</sup>

## Inclusion criteria:

- Male, Bahraini residents under 65 years.
- English or Arabic language speaker.
- Diagnosed with HF for at least one year.

#### Exclusion criteria:

- Males over 65 years of age.
- Diagnosed with a mental disorder.
- Inability to communicate (e.g. stroke, on ventilator, speaking disabilities, etc.).
- Patients with major comorbidities other than HF.
- Did not speak English or Arabic.
- Not Bahraini residents.

# 2.3 Data collection

In-depth, semi-structured, one-to-one interviews were conducted using an interview schedule that consisted of seven open-ended questions (see Table 1). Probing questions were used to encourage the participants' to elaborate on data. The length of interviews ranged from 30 minutes to one hour. All the interviews were scheduled to accommodate the participants. The hospitalized participants were interviewed after the working hours to avoid interruption of doctors' rounds and procedures, and before the visiting hours. The interviews were all conducted in Arabic and were audio recorded. Four interviews were carried out at one of the hospital offices where privacy and quiet environment was achieved, and one of the interviews was done at patient's home, as he was unable to come to hospital due to his health condition. The sixth interview was done at the patient's room in the hospital at his convenience. In-depth, semi-structured, one-to-one interviews tended to be the optimal source of the rich data required. This type of interview is easily managed, allowing the participants to think and answer. An interview schedule is used to help the interviewer set the agenda, predict the sensitive topics and develop the questions in a flexible frame. [20] New York Heart Association (NYHA) Functional Classification was used in order to determine the level of functional limitation related to HF symptoms (see Table 2).

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#### Table 1. Interview schedule

- 1. Can you tell about your life after being diagnosed with heart failure (HF)? Possible prompts: what happens? How do you feel? How do you cope?
- 2. Can you tell me about your regular day after the diagnosis?

  Possible prompts: what happens? How do you feel? How do you cope?
- 3. Tell me about your lifestyle.

Prompts: what changed? In what way? What makes it better? What makes it worse? How do you feel about the change?

- 4. Tell me about your work? (if working)
  - Prompts: any change? How do you feel? How do you cope?
- 5. What was most affected in your life after the diagnosis?

  Possible prompts: what happens? How do you feel? How do you cope?
- 6. How do you see yourself in future?
- 7. Anything you want to add?

**Table 2.** NYHA functional classification

Class	Patients Symptoms
I	No limitation of physical activity. Ordinary physical activity does not cause undue fatigue, palpitation, dyspnea (shortness
	of breath).
II	Slight limitation of physical activity. Comfortable at rest. Ordinary physical activity results in fatigue, palpitation, dyspnea
	(shortness of breath).
III	Marked limitation of physical activity. Comfortable at rest. Less than ordinary activity causes fatigue, palpitation, or
	dyspnea.
IV	Unable to carry on any physical activity without discomfort. Symptoms of heart failure at rest. If any physical activity is
	undertaken, discomfort increases.

Translation and transcription was carried out by the first author, a native Arabic speaker. This process ensured taking account of comments and observation that were noticed during the interview that may have being significant to the data analysis.

#### 2.4 Pilot interview

A pilot interview was conducted with a patient attending outpatients. The interview was short and the participant did not disclose much information answering most of the questions with "I am fine now" and "I am following the treatment and advice". Following this interview the researcher decided to use an interview schedule with seven open-ended questions. In addition a decision was made to include both inpatients and outpatients in the sample. The data from the pilot interview was not included in the study sample because of the thin quality of the data.

## 2.5 Data analysis

IPA procedures of data analysis were adhered to as recommended by Smith et al.<sup>[20]</sup> His six step method involved, moving from one interview to another and repeating each step in each interview. Trustworthiness was ensured as recommended by Lucy Yardley,<sup>[25]</sup> who suggests that demonstrating sensitivity to the context of the study, and the sociocultural setting of the study with a focus on the relationship

between the investigator and participants, is a key component of rigour and trustworthiness. In this study, this process began with the formulation of topic questions. The author in conjunction with the second author decided to use open ended questions and not to explicitly refer to issues of a of a sexual nature. If the participants themselves brought up sexual issues then the first author gently probed for further description Support was provided when emotional reactions occurred while expressing painful feelings. For example interviewing was stopped with one of the participants in order to provide the emotional support.

The second quality required is commitment and rigour. Commitment was represented by the persistent engagement with the study topic, and developing the skills and methods. Rigour depends on the adequacy of sampling in term of the ability of the sample to provide the information for comprehensive analysis (saturated data) and not upon the size of sample. In this study, the researchers showed commitment through the degree of concentration with the participant while conducting the in-depth interviews, and acquiring the needed skills. [20] The interview questions were practiced initially with a colleague from the healthcare field in order to assess the clarity of the questions and the method of running the conversation. The practice interview was recorded and repeated. Moreover, the pilot study revealed some weakness in

the interview skills that were expressed to the researcher's supervisor  $(2^{nd}$  author) and feedback comments were taken and corrected. Active listening was engaged in during the interviews and probe questions were used to clarify and obtain more details. In the processes of sampling, the researcher recruited the participants according to the inclusion criteria. The homogeneity of the sample was ensured, all the participants were resident in Bahrain and being treated in the same institution, male, and diagnosed with HF for almost one year. As all provided rich data about the experience with HF, a sample of six was deemed sufficient as the data was saturated with no new themes emerging.

Transparency and coherence is the third quality proposed by Yardley. Transparency refers to how the data is presented. The clear description of the research process starting from enrolling the participants, to interviewing and interpretation safeguards transparency.<sup>[20]</sup> The participants in this study were enrolled from two different sources, an existing clinical study and inpatients. The interviews were recorded and coded by initials to maintain privacy, and transferred to the researchers personal computer and deleted from the recorder immediately. The interviews were translated and transcribed by the researcher, followed by coding and analyzing each interview, one after another to avoid interference of previously obtained data emergent codes and themes were discussed with the academic supervisor. Coherence is reflected by the degree of which the research question fits the perspective of the adopted philosophy, methodology of data collection and analysis used. Thus, a qualitative researcher should place herself in the position of the reader and judge if the whole process of the research is fit and coherent with the research question and aim.[20,25]

The last principle proposed by Yardley is the impact and importance. This broad concept proposed that what is impor-

tant in the end of the research is how it will have an impact, how important, interesting and useful the presented data are. This study was the first of its kind in Bahrain and the Arabian Gulf States, as no published work was found in any search engine up to the year 2013. Furthermore, the study results were significant, where the HF burden on the participant was represented in many aspects. The results of the study can be used in producing a comprehensive educational package for HF patients in Bahrain covering multiple dimensions of the health condition. Furthermore, the results revealed a significant need for counseling and support system to HF patients in order for them to communicate their concerns and find strategies to cope with their health condition with the help of professionals.

## 3. RESULTS

The IPA analysis of the interviews' transcripts produced 12 super-ordinate themes from the six participants. Superordinate themes were identified through finding the pattern between the emerged themes and then naming the cluster. Developing the super-ordinate themes involved looking for the opposite relationships between emerging themes; this step is referred to as polarization, where the researcher focuses on the differences rather than similarities.<sup>[20]</sup> Following this integration of the data, the final step involved identifying patterns across the cases and examining the connectivity. The connected themes were then pulled together and grouped under one comprehensive theme. The average age of the participants was 62 years, and the duration of HF symptoms was between 2-4 years except for one participant who stated that his symptoms started in early years when he was diagnosed with ischemic heart disease at a young age (before his  $25^{th}$  year). The demographic data of the six participants is presented in Table 3.

Table 3. Demographic data

Initials	Age	Marital status	History of HF symptoms	Comorbidities	Working status	NYHA Class
A.A	61	Married	2 years	Ischemic Heart Disease (IHD)	Retired	III
M.M	64	Widower	4 years	Diabetic (DM)	Retired	IV
Q.A	62	Married	4 years	Stroke, IHD	Resigned	III
F.M	63	Married	3 years	DM, valve replacement	Part-time	III
M.J	62	Married	25 years.	DM, Hypertension	Works	II
S.A	65	Married	4 years	IHD	Retired	II

The three dominant themes are presented in Figure 1.

# 3.1 Theme one: Physical burdens

The physical burden of the disease was given the priority in the findings, as this was the predominant theme across all the interviews.

#### 3.1.1 Symptoms

While physical symptoms of the participants varied, most described feelings of suffocation, especially at night while sleeping.

# **Theme One:** Physical Burden 1. Symptoms 2. Effect on Daily Activities 3. Poor Sleeping Patterns Theme Three: Theme Two: Living with HF **Psychosocial Aspect** 1. Lifestyle and Behavioral 1. Disturbed Identity Modifications 2. Relationships 2. Religious Beliefs 3. Social Context 3. Awareness

Figure 1. The three dominant themes

M.J: "I felt after that I was suffocating at nighttime while sleeping. I was suddenly waking up at night out of breath."

Other participants stated that they frequently experienced shortness of breath (SOB) when active or even at rest, and sometimes associated this with palpitations and feelings of exhaustion.

F.M: "I get it when I am even sitting. I'll have shortness of breath, very tense feeling, whenever I'm walking to the mosque I'll have palpitation."

Tiredness appeared to have a major effect on daily living and in some cases; it was the first sign of the sickness that led to seeking medical care.

M.M: "I told him why I am getting tired and so on, he told me you have weakness in your heart muscles ... But later I had palpitation, tiredness, and sometimes sweating with minimal effort... I am tired, tired."

One of the participants expressed the loss of concentration and observational skills after being diagnosed with HF.

M.M: "I don't have the confidence in my driving skills, my driving skills are not the same.... concentration, observation, not the same... from the tiredness I am getting, its like I'm being confused about my abilities to drive again after having this kind of disease."

Physical symptoms were the dominating subject throughout the interviews, all participants agreed on the huge effect of those symptoms on their entire life, including the daily activities of living.

The participants considered themselves too young to be experiencing such tiredness.

F.M: "Nothing else but tiredness, nothing else. For example

now, if I go down the stairs, going to the shop I'm getting tired, I wasn't getting tired before!"

# 3.1.2 Effect on daily activities

The effects of HF on activities had consequences that extended to even social living. Participants expressed their frustration of being not able to attend their families' and friends' occasions, and described how tiredness and the constants feeling of sickness made it impossible to be socially active again.

M.J: "I was getting tired even from carrying small things, even when I was carrying my young child, and she was little, weighing not more than 6 or 7 k.gs, so I was feeling tired, so I cannot carry anything."

M.M: "I was going for funerals whenever I heard someone passed away, marriage parties, and I don't go only for funeral visits, but I was going to the burials in the cemeteries as well, and I was visiting my friends whenever someone comes in my mind. But now, the sickness hinders you, how I can go anywhere now? Even the clothes, the person will think how I'll change my cloths now and get ready? Its exhausting to change your clothes."

The physical burden of HF also affected participants' ability to engage in paid employment. This also affected families due to the decreased financial contribution to the family budget.

Most of the participants had to leave their employment following diagnosis, with some retiring early. One of the participants stated that HF affected his job significantly. Mr. F.M was sad that his output at work was less and his working hours were reduced tremendously. This participant, however, insisted on maintaining employment even though he reached the legal age of retirement.

F.M: "the Imam should be in the front and leading others, but I cannot do that now! And I only do it while sitting on a chair. I lead the prayer one time in a week now, imagine (he looked sad about it) only on Saturdays! Because I cannot anymore, I am tired."

M.J: "when I was admitted in the hospital that was the only time I stopped going to work."

The effect of HF symptoms on the activities appear to be related to the inability to manage the physical symptoms that led to tiredness and exhaustion, which was exacerbated by an inability to get adequate amounts of sleep and rest during the day and night.

#### 3.1.3 Poor sleeping patterns

Participants experienced poor sleeping patterns. The inability to fall asleep, maintain sleeping and disturbed sleeping were some issues that were mentioned by participants. Describing the sleeping habits as "poor" was stated by one of the participants saying that he was forced to wake up frequently to go to the toilet, reflecting on the side effects of the HF treatment.

S.A: "I was sleeping normally before, but what brought me this time is the suffocation I was getting while sleeping."

Q.A: "I sleep for short time, in 24 hours, only an hour and a half, and interrupted as well."

Some of the participants stated that sleeping while sitting was the most convenient position to rest, laying down to sleep or sleeping on sides was not an option due to inability to breathe or the suffocation feeling that would dominates.

M.J: "I wasn't able to sleep but sitting like that (he was referring to his current position during the interview) I can't sleep on right or left, or on my back, even my wife arranged a chair that I can sleep on at night, and they did all the arrangements for me to sleep. Still, I was awake until morning, and if I sleep I'll suffocate."

F.M: "it means that I can sleep better if I am sitting this way, because if I am sleeping on my left side, my heart beats faster, and I'll be having difficulty in breathing, so I cannot, as long as I am sitting, I'll be comfortable."

While the physical burden theme was the dominant theme due to its high impact on participants' daily life activities, the psychosocial aspects of the disease were intertwined with the physical burdens of HF, and in some cases the physical aspects of the disease resulted in emotional and social distress.

#### 3.2 Theme two: Psychosocial aspects

Participants stressed that different situations resulted in them feeling under psychosocial stress. This was described by one participant feeling "horrible". This theme consisted of three integrated sub-themes; disturbed identity, relationships and social context.

# 3.2.1 Disturbed identity

Living with HF initiated changes in participants' identities. A lack of physical fitness resulted in them being unable to fulfill previous roles for example participating in sport or sexual activities and also, recreational and social involvement.

F.M: "But I cannot do any sport activities anymore, and other activities as sexual activities stopped."

In relation to manhood, following HF, some of the participants expressed the inability to perform as a partner during sexual activities.

M.J: "even the things between wife and husband are different now."

M.M: "sex, as I remember once when I had sex for 10 minutes, it felt like walking for 2 hours... it kills you ... I stopped."

Being treated as a sick person, and labeled sick and dependent on others for care was difficult for some participants.

M.J: "its painful to me to see anyone sick now, because I know how it feels to be sick and the need of family and others to take care of... life changes when the person feels that he needs others to take care of him."

The effect on the physical fitness had a great impact on the participants with some expressing anger and frustration. The expression of their emotional suffering was somehow related in their acceptance to the diagnosis and ability to cope.

The participants expressed a mixture of feelings, being sad about their current health condition, frustrated, helpless, angry, regretful, and feeling hopeless about their future.

F.M: "I don't know, psychologically I feel that I am fed up, but I am fine when sitting home, seeing others all normal."

On the other hand, some displayed a positive way of thinking and reflected positively on their experience and were optimistic about their future.

M.J: "I like arranging the house myself, I like doing things myself, because I don't want to feel helpless, I cannot live with the feeling of being helpless."

Two of the participants expressed the feeling of regret regarding the past. The unhealthy lifestyle habits they had engaged in, and their regret at this.

M.M: "I wish we were able to go back in time... To go back in time and try to avoid the mistakes we have committed in our life. It was a simple decision to make... In my youth I was drinking, smoking and stayed out at nights. If I knew, I wouldn't do that, if I knew I wouldn't do that."

Regarding their view of the future, there were two contradictory viewpoints. One group of the participants was pessimistic about the future, while others were optimistic.

One of the pessimistic participants who was a widower without children who had the responsibility of raising his sisters and brother from his adolescents, described how he felt he had accomplished his future by seeing his siblings grown and raising their own family. Another participant expressed that he had no hope for the future asserting that he lost everything after being diagnosed with HF, and expressed how he is occupied by thoughts of death. When asked about the future, their answers were as follows:

M.M.: "like the water, tasteless but important. No future, just seeing the kids getting married, my sister's kids. I did it ... people are growing up, studying, getting married and kids; I came to the world having all this already. Children, responsibilities and problems, I had it all. And now what? Getting married for example? ... Nothing, no plans for the future."

Q.A: "Well, I have lost a lot ... I have lost the hope. I lost my passion, I got frustrated, honestly. It's a major thing that the person can get, this disease. And what scares me more in the matter of death and life, honestly. Its all in God's hand, but I knew a number of friends who were suffering from the same condition before and after my diagnosis, I know almost 4 or 5 others who got the same diagnosis and they are all dead now."

The optimistic participants had contradictory views of future. Some stated that they were optimistic about the future and trying to be active socially and enjoy life, whereas others expressed a confidence about the future as they had faith in God and they believed that all will be well if God wishes this for them.

M.J: "well, I am optimistic, that I will be fine if Allah will, and I have to follow the instructions, and I have to adopt with the idea that I am sick, until Allah heals me".

S.A: "I am looking for a better future, thinking positively and not thinking about bad things. And I am always traveling,[ out of Bahrain] at least twice a year. I'll take my wife and go out."

F.M: "I want to go out, but I let things in Allah hands, the most important thing is that my kids are beside me, and we

gather all the time, there will be no other problem."

The above contradictory expressions were all related to the worsening of physical symptoms, acceptance and coping. Crucially family support and family relationships gave some participants the strength to live with the challenges of HF.

## 3.2.2 Relationships

Relationships appeared to be a core aspect of support to HF sufferers. Generally, all the participants expressed that having a supportive family played a great role in overcoming the different burden of HF by being supportive, involved in the care, or providing the guidance to the participants on the treatment journey. Participants' wives in particular were mentioned:

F.M: "my family is so great, and are doing their best with me, and even the eye drops! I am not putting them, my wife is doing so, always her. Even my brothers and sisters, my children, they are always ready to stand beside me all the time."

M.J: "my wife is looking after my treatment, she's looking at what drugs I am taking."

Q.A: "Being sad, that makes my condition worse, I get affected. But my children got to know me better now and trying to avoid making me sad."

The importance of the participants' relationships with the health care workers (HCW) was not less important than with family and friends. Some of the participants related their health improvement with the positive relationship with HCW, where they had obtained the guidance instructions.

M.J: "everyone was so kind with me, doctors, Nurses, whether Bahrainis on non-Bahrainis. Telling the truth that they took good care of me."

S.A: "they are taking a very good care of me, even this admission, they are treating me good. When you call them they are attending. In the clinics, they are sending me for x-rays, like last year the doctor told me he wants to have an anther echo to check on my health and it was ok. Thank God they are doing the best to me. I am going to the appointments unless there was something serious stopping me."

In contrast, some participants complained of the lack of communication with HCW led to a lack of understanding of the condition starting from the diagnosis and following up to overcome the symptoms.

M.M: "I asked him, I told him why I am getting tired and so on, he told me you have weakness in your heart muscle, I told him how? No one told me before? He told me the Concor tablet that we prescribed for you is for the HF. No

body is sitting with us and telling you have so and so, or you will feel this and this because of this and that! Most of our diseases will know about them suddenly."

A.A: "I couldn't breathe at all, was the stomach involved too? Or the diet wasn't proper as no one told me what is the proper diet for my condition."

#### 3.2.3 Social context

The social context where the participants lived and interacted played a role in shaping their experience and had both negative and positive effects in living with HF.

Some participants described the neighborhood they were living in. For one participant, neighbors were his social support, and they were the people he spent time with, ventilating and entertaining.

M.M: "I put a chair outside the house door and sit there, the neighbors pass by sit and talk to me until 11 or 12 with prayer time, I enter the house to pray and then watch TV.... By 5pm, the men from the neighborhood come and sit with me inside or sometimes outside next to my door until the sunset, then everyone goes back to their homes and I'll stay alone, then back to watching TV."

M.M: "sitting alone for long time, yeah, being alone and thinking a lot and getting ideas ... I'm trying not to sit alone for long time, once I feel lonely I go sit outside next to the door, I don't stay alone."

That was the condition of the widower participant, who was suffering from loneliness most of the time. His loneliness had increased his symptoms, as well as making his decision to stop smoking more difficult.

On the other hand the majority of the participants in the study were married with children, and it was these family members who provided support.

M.J: "my wife did her best with me, and my daughters as well, and you are with them too, whenever I say (oh) they were rushing to help me, specially my wife. And they were looking after what I am eating, even my son in law ... my family was having a huge effect on me because I felt they are guiding me to what I should do."

S.A: "on Fridays, they are all gathering for lunch at home, and Tuesdays as well, weekly they are coming on Tuesdays and Fridays ... My wife is the one giving me the medication in the mornings. She's my nurse (laughing). Daily she prepares my medications ... keeping my drugs ready for me, she's great."

The only widower among the participants expressed loneliness of on his situation. condition. His only family were his sisters and a brother, all of whom were raised by him, had got married and he now lived alone. His loneliness had increased his symptoms, as well as complicating his smoking cassation decision.

M.M: "My family is my sisters and brother; I took care of them when my parents died. I have 4 sisters, and one sister from another father and a bother, I took care of them and raised them until they completed their studies and got married....And now they are in contact, mostly by phone, or passing by sometimes. You know, they have responsibilities and kids now."

Expressing the physical and emotional experiences was a challenge to the participants. It seemed that each one tried to recreate his way of living to accommodate the chronic condition in order to deal with it.

# 3.3 Theme three: Living with HF

Living with HF was the conclusive theme and showed the efforts that participants were making in order to live and cope with HF. Knowing that HF is a chronic and progressive disease, most of the participants were aware that the key element of living with the disease is to control the symptoms. Controlling the symptoms of HF depends on the changes that the participants created in order to overcome the sickness.

Theme three comprised of three sub-themes, lifestyle modification and behavioral modifications, religious beliefs and finally awareness of the disease.

#### 3.3.1 Lifestyle and behavioral modifications

The majority of the participants were aware of the lifestyle modifications that they were expected to achieve. However, many of the participants expressed a lack of knowledge or inaccurate information about their condition despite all stating they were taking the prescribed medications, but not fully strict about diet control.

F.M. "They told me you have this and that and you should work on yourself and cooperate with us. So now I am taking my hypertension medicine and following my appointments, and all is fine if Allah allows ... I coped with the disease as I have a say I am following 'you have to try defeating the disease', because if you surrender to the disease, you will be tired, so I copped with my condition as I know myself well."

S.A: "I was following the treatment and avoiding the forbidden things... For example the meat, I don't eat large quantities, only small portions... I only eat grilled fish... I don't drink the tea with sugar, I stopped that, even the sweets, I watch it on the table but I don't touch it. When they bake cakes, especially in Ramadan, I stopped eating all this in order to maintain my health."

Regarding the recommended activities, there was an agreement on the willingness to exercise, but most of them stated that it was difficult for them to even walk for short time due to the excessive tiredness following the diagnosis.

F.M: "I cannot move much, they told me that I have to exercise, but its too difficult as my heart is weak, and I have to climb the stairs to reach home."

M.J: "and trying not to exhaust myself more than what I can, not to show off in front of others, and say look at me I am still young!, no. I am doing what I can with the current condition."

The adherence to the treatment and lifestyle modification was a task that some of the participants failed to accomplish. Along with lifestyle modifications, the participants described some behavioral changes they had adopted to live with the disease. The main behavioral modification was anger management.

F.M: "I was going to the market, but gradually I stayed away from the market as it is tiring, problems and arguments, so I stayed away after."

M.J: "I adopted and started to be careful, first I have to stay away from being nervous and angry, and if someone tried to create problems to me and even if it was his mistake I would apologies to him."

A.A: "I'm trying my best not to lose my temper."

Getting used to the idea of being sick was one of the answers that the researcher got when looking up to the coping strategies adopted by the participants. Also, another participant was adopting by being optimistic, and trying to live his life normally by being socially active and being involved in entertainment activities, like traveling.

M.J: "I got used to the idea that I am sick now, and I have to work on eliminating the reasons that cause me to reach to this condition."

S.A: "I am looking for a better future, thinking positively and not thinking about bad things. And I am always traveling, at least twice a year. I'll take my wife and go out."

Although some have admitted that they were feeling better after walking, but most of the time they described how they suffered from exhaustion following minimal effort; all of which hindered them performing any activity. In contrast some were able to exercise as advised. They reflected on their improved health status and a great ability to cope with the condition. Accepting their condition and being optimistic provided them with the motive to change, along with their great faith on God's help with the sickness.

## 3.3.2 Religious beliefs

All participants were Muslims and shared similar religious believes. All reflected on their experiences and drew on their religious beliefs and their faith in God's will to sustain them. The majority used "I depend on God" to end a statement about his current sickness, while others pointed out to the importance of prayers and maintain the faith in God's fairness, along with being optimistic about being cured by the help of God.

F.M: "Anyway, I am living in this condition, and thanks to Allah I am doing fine ... I only wait for Allah mercy first, the one should not lose his faith and praying ... I want to go out, but I let things in Allah hands."

M.J: "I depend on Allah (God) and what Allah have decided for me will happen ... I am optimistic, that I will be fine if Allah well, and I have to follow the instructions, and I have to adopt with the idea that I am sick, until Allah heals me."

Q.A: "I ask from his kindness (God) the health and wellness, and to die peacefully doing the good thing he asked as to do."

Being faithful and trusting God was a privilege to the participants. Believing that there is always a possibility to be cured by God gave them the hope and strength to continue. This hope played a role in the behavioral changes they implemented in order to live with HF.

The final sub-theme was awareness. The variation of awareness regarding the causes of HF, and treatment and the way to manage the symptoms among the participants appeared from their statements starting from the diagnosis with HF and their adaptation to it.

#### 3.3.3 Awareness

Awareness of the causes of HF, treatments and the ways to manage the symptoms varied among the participants. Some had received sufficient amounts of information regarding their health condition, but following advice and instructions was their decision, and they were aware of this responsibility.

F.M: "the problem is the shortness of breath that you are getting, and you can deal with it by losing weight or decreasing the water intake. The dietitian came to me, and told me what to do and what not, but how to follow all of this now? I don't eat much now, I eat little, but I like oily food ..."

M.J: "I felt that I have the desire to live and that I must cooperate with the doctors, and not to depend on the doctor's treatment and help only, but I have to cooperate with the doctor and follow his instructions word by word. And I felt that I have the desire to help them the way they helped me, and the way they are trying to treat me, I should treat

myself."

On the other hand, some of the participants complained of lacking sufficient information regarding their disease from the first day they were diagnosed with HF, reflected on their compliance with treatment, as they simply were not informed.

M.M: "The doctor is coming and writing the drugs, and asking us how are you and how are you feeling now and that's it, the drugs we are taking we do not know for what? Help in what? When to have it? When we shouldn't?"

Other participants were aware of the hereditary proposition of HF, and they related in a degree the possibility of getting HF through generation.

M.J: "Because my father died with the same disease, he was in the hospital, my father 'may Allah have mercy on him' died on 1961, and my brother as well, he was in Jordan for treatment for heart problem."

A.A: "the disease came from the elder generation. I have five cousins with heart diseases."

The findings of this study revealed three main themes reflecting the life of men living with HF. While the three themes were all related and interconnected, the physical burden appeared to be the main cause of the psychosocial suffering and directly affected coping strategies with the progressive illness.

#### 4. DISCUSSION

The findings of this interpretive phenomenological study of men living with HF concurred with previous studies that the physical symptoms of HF are the most dominant burden.[2,5,6,26,27] The constant feeling of tiredness and exhaustion contributed to a low quality of life, all of which led them to seek medical care. [5] The sudden onset of symptoms, and the subsequent changes that occurred in the men's life was shocking to them, and they never imagined that they would have this condition that altered their physical fitness.<sup>[26]</sup> The men in this study appeared to be confused about the diagnosis, and this confusion affected the their acceptance of the diagnosis and decreased their awareness regarding the physical symptoms, a finding that concurred with a previous study. [28] This tiredness led to a reduction of physical activity especially as the disease advanced. The lack of energy to perform the daily activities of living resulted in increased dependency on others usually a spouse or family member. [26] This increased dependency for some, in this study, led to anxiety.[2] The reduced level of activity also affected the social life of the men and for some, resulted in social isolation. In this study the degree of disabling physical symptoms

reduced men's ability to work. This had major consequences for some of the younger men, as they considered paid employment an important part of their masculine identity. This also had financial implications for them and family members. Their jobs had provided the feeling of worthiness, and being forced to retired or reduce working hours created feelings of emptiness that affected their self-image. [12,26] In this study the men who were in better physical condition and able to engage in paid employment were less anxious and reported a better quality of life. [5]

In this study, sleep dissatisfaction was a significant finding. Satisfaction with sleep is a matter of personal expression; most of the men expressed dissatisfaction with their quality of sleep. Sleep and rest are strongly related to the disease symptoms, complications, and treatments' side effects. The inability to fall asleep or maintain sleep, recurrent awakenings to urinate, and nocturnal dyspnea are the major causes for low sleep quality among HF patients. [29] In this study the men found sleeping in the prone position difficult and frequently slept sitting upright. Being treated with HF medications should work to ease some of the sleepiness symptoms like feelings of suffocation; using extra pillows to aid comfort however, because of lack of knowledge and in some instances noncompliance the men in this study experienced difficulties. Additionally, sedentary lifestyle and inactivity during the daytime may have contributed to the sleeplessness during the night. Recurrent hospitalization, and other comorbidities, as well as anxiety and depression were also contributing factors.<sup>[30]</sup> All of which may have contributed to decreased cognitive impairment among the men in this study.[12,31] Worsening physical symptoms contributed to a significant degree of cognitive impairment, [31] a factor that also shaped recurrent hospital admissions and in some cases no compliance with treatments.[32]

In this study being a "man" diagnosed with chronic progressive condition challenged the participants' masculinity. As in other studies, the men in this study expressed their frustration regarding the lose of their masculinity and their role in the family and society. [12,13] Living in a Muslim society, men are tasked with the responsibility of being the main breadwinner in the home. They are also expected to be the disciplinarian with the children. Despite the involvement of females in the work place and contributing to the family budget, the man is still considered the primary source of financial support. Some participants expressed the feeling of helplessness at their inability to perform simple tasks at home, and their inability to run errands. Depending on others altered their self-image of fatherhood and "being the man" in the family carrying out traditional masculinity roles. The issue of sexuality for the men in this study was a sensitive

area and while the men expressed their inability to engage in a sexual way with their partners discussing it during the interviewer was tentative, as discussing sexual matters with stranger, especially a female researcher may by some be considered taboo. Of the six participants, only two stated that they had sexual difficulties following diagnoses. This is a finding that concurs with others that revealed a significant reduction of sexual activities due to tiredness and impaired physical fitness, a factor that in turn that negatively affected the marital relationships.<sup>[3,12,33]</sup>

Social support is a very important element in improving HF patients' compliance to treatment and improving the quality of life and it's reported to be a strong predictor of hospitalization and mortality in HF patients.<sup>[34]</sup> In this study married participants with children reported a great degree of social support from their family compared to single men. Families played a major role in the physical recovery after the diagnosis, specially wives. Wives were supportive and helped the participants to adhere to the plan of the treatment in most of the cases by the diet restrictions, and preparing the medications on time. In general married participants enjoy more care by others, particularly by the spouse in some tasks like reminders to take medications. Strong social relationships and emotional support positively influence in decreasing stress and anxiety, and higher level of adherence. [35] On the other hand, being married with children affected the participants negatively in some cases. Being unable to work and earn money after the diagnosis increased the burden on the participants and challenged their role at home. Besides, overprotective families enforced the sick role for some participants and disturbed their masculinity by making them feel weak and helpless. Social support could have negative influences when the family and friends were unable to fully understand the nature of HF and significant others involved in care might undermined the HF patients perceived abilities and confidence in their abilities.<sup>[12,35]</sup>

In this study, the relationship of HF patients with HCWs also defined the patients experience with the disease. Lack of communication created gaps in care, and affected the efficacy of the education and information being provided. HF patients usually experience short-term memory loss, fatigue, and confusion. Those factors act as communication barrier between the patients and HCW, which affect the tendency of patients to ask questions, and frequently resulted in some of the men considering HF was part of the aging process.<sup>[29]</sup> Lack of trust played an important part in the poor communication with HCWs. Poor communication between patients; families and HCWs will certainly act as a barrier for effective discharge plans and follow-ups.<sup>[36]</sup> In addition, HCW tend to react with patients' condition and complaints from

the perspective of seeing and treating the "disease", which focused only on the etiology and the symptoms of HF with minimal attention is given to how the disease affected individuals socially and personally.<sup>[37]</sup> Viewing patients' from an "illness" rather than only a "disease" perspective may help HCWs to more fully understand patients suffering and of how they can assist them to live better with the illness. As HF patients frequently present with many comorbidities, good communication with patients and their families will surly clear the picture about their condition and positively effect their coping strategies and health outcomes. In this study, another factor shaping communication was a lack of awareness about the psychological needs of HF patients, thus resulting in a comprehensive assessment and treatment plan that adequately covered the physical and psychological needs of patients living with HF.<sup>[36]</sup>

Given all the anxieties and physical symptoms that HF patients' experience, it is understandable if they do not strictly follow medical advice. HF patients are required to modify their lifestyle, career, social involvement, diet, sleeping habits, and most of other aspects of their life. Thus, constant support from family, friend and healthcare workers is mandatory so that they may come to terms with their condition and make the required lifestyle changes. On the other hand, in this study faith and surrender to God's will appeared to be an important strategy to overcome the emotional distress after being diagnosed with a life-changing condition. Trust in being cured with God's help, believing that one should keep praying and asking for His mercy was another way of coping. Almost no study that has been published has discussed how spirituality and religious beliefs aid coping among Muslims with HF or other chronic diseases. However in other religious frameworks, studies have shown that spiritual well-being is strongly related to reducing and preventing depression, and indeed improves the quality of life. [38] Being religious and accepting the diagnosis is linked to positive experience with HF and enhances the meaning of life, [4] whereas spirituality was an essential way to manage the depressive symptoms, and the patients who were involved in religious practice were able to recover from depression faster than the non-religious.<sup>[39]</sup> While another study showed that being religious, faithful and remaining hopeful is not a common coping strategy.<sup>[14]</sup> Our study revealed that HF patients in Bahrain depend greatly on their religious beliefs to cope, however, for some the emphasis on religious beliefs led them to believe that they did not need to make lifestyle changes and to comply with treatment regimes.

## 4.1 Recommendations

Understanding the challenges that men with HF face in their daily living should enable nurses to help the patients to live

more successfully with the challenges the illness presents. Having in depth knowledge of the men's concerns should help nurses to educate the patients and help them to develop strategies to support them. Supports should be both of a physical, psychological and educational nature and should be provided to the patients from the day of diagnosis. Nurses with their knowledge can be a rich source of support. Nurses can give guidance and education, and the family can also be involved in the care for the inpatients and outpatients. Family involvement in care eases the burden of the patients and can provide a solid support system along with the health professionals. Planned educational workshops can provide a great help to the patients and their families in order to understand and grasp the essential information about HF causes, symptoms, treatment, prevention of symptoms aggravation and coping strategies.

The authors recommend that future research could focus on the psychio social aspects of family members living with a significant other diagnosed with HF.

#### 4.2 Limitations

Being a novice researcher created a lot of pressure in understanding the general terms and steps of research. Recruitment of the participants was also a challenge. Most of the patients that were contacted over the phone to participate refused, stating that they were fine and did not want to participate in any study. The burden of coming to the hospital for the interview may have been a reason for refusal to participate. In addition, most of the inpatients admitted with HF were in a critical condition, either on mechanical ventilation or too sick and tired to conduct an interview that might take more than 30 minutes.

Furthermore, there were no specific HF databases existing in Bahrain. After a prolonged search, the official statistics only revealed the number of patients admitted with pulmonary oedema and Cardiomyopathies, and no specific statistics about the number of HF cases. This created a gap in the literature and difficulties to compare the situation in Bahrain and other countries. Due to the lack of data, the researcher had to rely on international statistics to stress on the importance of the research problem.

#### 5. CONCLUSIONS

The study explored the experiences of men living with HF in Bahrain. Improving the experiences of HF patients is a shared responsibility between health care workers, the patients, families, society, and the governmental institutions as well. From the day of diagnosis, positive relationship should be established with HF sufferers and their families, where the patient should be the center of care. Health care workers, especially nurses, should obtain the required knowledge to manage HF cases and provide the required education and support. Moreover, societal awareness should be increased for the early detection of HF symptoms, and support campaigns should be initiated for HF patients. With the cooperation of different governmental institutions, a support system can be created in order to improve the experiences of HF patients in Bahrain and help them overcome their difficulties and distresses.

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#### CONFLICTS OF INTEREST DISCLOSURE

The authors declared no potential conflicts of interest.

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