

ORIGINAL ARTICLE

Critical Factors in Quality of Life: A Qualitative Explorations into the Experiences of Malaysian with Heart Failure

Nor Firdous Mohamed¹, Nor Azwany Yaacob², Aizai Azan Abdul Rahim³, Oteh Maskon⁴, Mohamed Hatta Shaharom⁵, Othman Lebar¹

¹ Department of Psychology and Counseling, Faculty of Human Development, Universiti Pendidikan Sultan Idris, 35900 Tanjung Malim, Perak, Malaysia

² Department of Community Medicine, Universiti Sains Malaysia, 16150 Kota Bharu, Kelantan, Malaysia

³ National Heart Institute, No 145, Jalan Tun Razak, 50400 Kuala Lumpur, Wilayah Persekutuan, Malaysia

⁴ Universiti Kebangsaan Malaysia, Jalan Yaacob Latif, Bandar Tun Razak, 56000 Kuala Lumpur, Wilayah Persekutuan Malaysia

⁵ Dewan Bahasa dan Pustaka, 50460 Kuala Lumpur, Malaysia

ABSTRACT

Introduction: Heart failure (HF) prevalence is increasing in Malaysia and brings about significant poor outcomes especially on the patients' wellbeing. Despite the devastating physical symptoms of HF experienced by patients, other social consequences on patients are often not discussed by their health care professionals. Hence, this qualitative study aims to explore and understand the quality of life (QOL) for patients in Malaysia of various ethnicity who have been diagnosed with heart failure. **Methods:** Nineteen (n = 19) patients with recurrent HF were recruited via purposive sampling. One-to-one semi-structured interviews were conducted after patients' informed consent was obtained. The aforementioned sessions were audio-recorded and transcribed verbatim. Finally, the transcribed data was analysed through Braun and Clarke's framework for thematic analysis. **Results:** The findings revealed that Malaysians with HF reported either positive or negative experiences related with QOL which had an effect on their well-being. Four main themes emerged included physical, psychological, social, and spirituality. Interestingly, cultural and beliefs consideration were important to understand these QOL themes of HF patients as a whole, especially in Malaysia's multi-ethnic communities. **Conclusion:** Informants were able to give vivid descriptions of living with HF experiences and the way it affected their QOL due to the disruptive and uncertain nature of HF in four major themes. However, the individual themes of QOL in HF patients need to be comprehended in detail including the local cultural perspectives, particularly by health professionals who deal with HF patients of minority ethnicities, in order to improve treatment and health outcomes.

Keywords: Quality of life, Heart failure, Qualitative, Malaysia

Corresponding Author:

Nor Firdous Mohamed, Master of Clinical Psychology

Email: norfirdous@fpm.upsi.edu.my

Tel: +6015-48797737

INTRODUCTION

The prevalence of non-communicable diseases (NCDs) are increasing at an alarming rate, which is a main cause of mortality rate among adults (1). Heart failure (HF) is one of the most prevalent NCDs that commonly manifests in adults aged above 65 (2). Evidently, the prevalence of HF in Malaysia is the highest worldwide (6.7% vs 0.5 – 2% respectively), with a high risk of premature death (19.6%) (3). According to Malaysian studies, HF has accounted for 6 – 10% of all hospital admissions nationwide since 1999 (3–6), in addition to being an important cause of hospital readmissions. Furthermore, HF patients often face unfavourable prognosis, huge medical expenditure, and prolonged

socioeconomic burden (6).

Poor quality of life (QOL) has often been attributed to general physical deterioration, frequent HF-related hospitalisations, depression, adverse effects of treatment, as well as social limitations (7). HF patients undergo a more difficult adjustment process and hence face a decline in their Quality of Life (QOL) to cope with the illness symptoms compared to other chronic disease patients such as obstructive pulmonary disease, unstable angina, stroke (8). The survival rate of HF patients is worse than those with cancer (9). This often overwhelms the HF patients due to the negative consequences of the disease which impose debilitating effect on their overall QOL (10).

Previous researchers have highlighted the importance of qualitative studies in gaining a better understanding of QOL for the development of more comprehensive patient self-management programmes (11). For

example, Freund et al. (12) emphasized on the need to take into account the patients' preferences prior to the commencement of treatment, with aims to promote HF patient compliance towards their therapies, which in turn might reduce the rate of hospital readmission. Reduction in hospitalization for HF is important to lower the financial expenditure and economic burden of HF patients caused by is illness (9). Hence, QOL is an important determinant towards improvement in survival rate of HF patients which require a different type of intervention that takes into account physiological, psychological and social considerations (8).

A survey based study conducted in Malaysia has suggested that there is a need for a qualitative exploration and understanding into the heterogeneity of the risk factors that contribute to specific cardiac concerns among different ethnic groups (13). To date, several research have explored on the factors which affected treatment experiences among the HF patients, but limited explanation on the factors specifically on QOL from the multiple ethnicities perspectives (14). Owing to this suggestion (13), there is a need for a qualitative exploration into the QOL factors based on the patient's personal experiences of living with HF, and how this illness interferes in their lives, disrupts their ability to perform daily routines and cause emotional instability(15). Unfortunately there is lack of evidence-based guidelines from studies in Asian societies on effective interventions for the minority samples (16). Hence, important factors emerged from these qualitative findings would benefit towards the development of a specially tailored intervention strategies with cultural elements consideration that could enhance the effectiveness of treatment care (17). Therefore, the purpose of this study is to explore and understand the QOL of multi-ethnic heart failure patients in Malaysia.

MATERIALS AND METHODS

Study Design

A qualitative design consisting of semi-structured face-to face interviews was used in this study. Face-to-face interviews was used because this method provided the informants with comfort and privacy as they shared their experiences. This study is an inductive exploration of the patients' experience of living with heart failure by investigating the subjective phenomenon as described by the patient. This study adopted an exploratory case study approach commonly used in psychological health related studies (18). This approach facilitates an understanding of the meaning of quality of life through the informant's reflections on their recovery experiences with HF. Furthermore, according to Smith (19), the case study method allows the researcher to explore information about individuals' situation such as their behaviour, thinking and perception of the environment around them, hence the case of particular individuals in a specific situation can be described.

The overall qualitative process was in accordance with the qualitative framework of Miles & Huberman (20). The said framework was selected because it clearly articulated the decision-making processes and procedures in thematic analysis.

Data Collection

Informants were selected via purposive sampling. Purposive sampling strategies were based on several selection criteria such as the severity of heart failure symptoms, socio-demographic background and predetermined factors in QOL which were elicited based on the ongoing emerging issues starting from the initial informants (21). The sampling recruitment was conducted with assistance from the doctors' referral which based on the aforementioned criteria (21), and upon consent was granted the interviews were conducted at the informant's bedside in the hospital's ward since most of them are immobilize. Data were collected using semi-structured in-depth interviews, and the interviews protocol was guided by findings from QOL-related scales reviews (22) and qualitative based studies among HF patients in Malaysia as reported by Ming et al, (23) (Table 1). The semi-structured interviews were employed as they were suitable for explorations into the perceptions and opinions of the respondents regarding complex as well as sensitive issues (24). Whereas, the semi-structured interviews protocol used by the interviewer mainly to keep the interviews process on track, however details explorations through open ended questioning and probing were conducted to deepen or clarify the information during the interviews (24). The interview process also encompassed hermeneutic inquiry prescribed in the phenomenology approach, which involves the informants making sense of HF illness experience (18). Each face-to face interviews that comprised of one informant and one interviewer, which lasted for 45 to 60 minutes.

In order to enhance the rigor of the qualitative data, the informant's validation was assured during the interviews and analyses of the qualitative data. Data collection was conducted in a real-life setting on a purposively-sampled homogenous population. This study did not employ

Table 1: Semi-Structured Interviews Guide

What are the symptoms that you have due to HF?
How do you cope with these changes?
What are the physical issues that you had encountered due to HF?
How do you feel after being diagnosed with HF?
How is your social interactions with family members after having HF?
How is your social interactions with your spouse/partner after having HF?
How do you perform you daily activity living after diagnosed with HF?
How do you cope with your routine demand despite having the HF symptoms?
What is the self-care routine you have to do as HF patients?
What are the factors that helps to cope positively with HF symptom?
What are the barriers for you to cope with the HF symptoms

extrapolations from artificial settings (e.g. laboratory to real-world extrapolations), which meant that it had high ecological validity (18). The researcher made field-notes immediately after every interview, including a summary of the areas discussed, the researcher's interpersonal conflicts and nonverbal observation on the informants during the interviews, which all these information were reviewed in reflexivity sessions between the lead author and co-researchers to ensure the quality of each interviews particularly. The main purpose of the reflexivity sessions was to help the researchers identify and select new informants to answer the research questions. Reflexivity also prevented the incorporation of personal judgements and interpretations, confirmed the researchers' understanding of the data, highlighted the emergent issues that were noted by the fellow researchers, and maintained a positive unconditional state in every interview (18). Whereas, prior the analysis the interviews were audio-recorded audiotaped and transcribed in verbatim (18). The researcher then checked for the accuracy and quality of the transcripts by listening to the tapes as well reading through the transcripts a number of times. The audio recordings of the HF patients and field notes taken were also cross-checked for the similarities and differences in the understanding of the HF patients' experiences. According to Barbour (25), this process helped to determine the validity of the study via evaluations of the similarities and differences be in the verbal experiences HF patients, as well as non-verbal observation during the interviews. Finally, during the analysis, the final outcomes of the analyses of emerging themes were sent to external experts who had at least 5 years of experience in qualitative research for peer-debriefing. The objective of this exercise was to check the similarity of the coded themes with the informants' original quotes, as well as the relevancy of each themes with this study main aims (26).

Ethical consideration and Sampling

The informants were recruited over six months (September 2017 to August 2018), from the National Heart Institute (IJN) – a tertiary cardiac referral hospital in Klang Valley, Malaysia. The inclusion criteria encompassed recurrent heart disease inpatients or outpatients who were diagnosed with HF and assessed by a cardiologist, apart from fulfilling the diagnostic criteria in the Malaysian Clinical Practice Guidelines (CPG) for the Management of Heart Failure (27). Further criteria included patients' reduced left ventricular function (ejection fraction of less than 45%) and New York Heart Association (NYHA) classification of at least NYHA II. NYHA, whose grades range from 1 to 4, categorized heart failure patients according to the extent of limitation in their physical activity. An increase in grade corresponded to a greater symptom severity (27). The patients also had to be able to communicate in Malay since the interviewer is a native speaker of Malay, and given inform consent. The study protocol was approved by the National Heart Institute Ethics Committee (RD5/08/15).

The sample size was based on the concept of data saturation and homogeneity of the samples. Besides that, the phenomenological interviews approach also focusses on the depth, richness and quality of data rather than on quantity (28). A number of fifteen informants were determined as adequate for a qualitative research (29). In this study, the sample was deemed to be homogenous in terms of their HF diagnosis, and sampling was terminated due to saturated emerging themes of living with HF illness experience. Data were analysed immediately after each interview and based on data quality we stopped at nineteen informants, which was adequate for a qualitative based study as in Merriam (29) and they were of the three major Malaysian ethnic groups: Malay, Chinese, and Indian. Since this study is not intended for generalization, balance ratio between all three major ethnic groups of Malay, Chinese and Indian are not prerequisite.

Analysis

The qualitative analysis in this study was in accordance with the qualitative framework of Miles & Huberman (20). The said framework was selected because the decision-making processes in findings the themes is clearly articulated. There are three concurrent activities under this framework, namely data-reduction and -displaying, conclusion-drawing, as well as data verification (20). Data reduction concerned the making of analytical choices of data to be extracted, coded, and summarised. It also helped sharpen, sort, focuses, discard, and organise the data. Evidently, all these processes were interrelated in that the researchers were constantly switching among the aforementioned activities throughout the analysis.

The thematic analysis process began while interviewing was ongoing. The interview schedule was updated based on early analysis to include emerging questions on QOL such as spiritual well-being (Table I). All interviews were analyzed by using thematic analysis based on guidelines specified by Braun and Clarke (30) that involves: i) familiarizing the data through listening back to the audio recorded during the interview session and reading written transcript based on the audio recorded several times in order to fully understand the implicit and explicit information provided by the HF patients, ii) generating initial codes done in vivo, whereby the words or short phrases from the informants' own language in the data were coded from the raw data by arranging the code accordingly to the informants key answer to the interviews questions, iii) searching and classifying the themes by developing a thematic map visualization at the initial phase by sorting the codes into different themes; subsequently, the overall thematic map was restructured in a table format which enabled the researcher to establish the relationships between the codes, themes, and subthemes, iv) extensive process of reviewing the generated themes patterns by at least 50% agreement from the informants was conducted

iteratively by reconsidering the code that is classified under the theme to make sure if the code is relevant; besides that, the main author also actively sought reviews with co-authors and the expert panel to ensure that the themes developed are relevant to the codes, v) themes defining and labeling was conducted specifically based on the theme meaning and descriptions, and also distinguishable from other response by the informants, and finally vi) based on previous analysis, the themes are converted into a report that is interpretable by using some examples from the transcripts related to this study's research questions. Tables of themes were drawn up for major codes as in Table II. The thematic analysis process from i – iv were relied on qualitative framework of Miles & Huberman, (20) of data reduction process that concerned the making of analytical choices of data to be extracted, coded, and summarised. This study not assisted by any computer-assisted qualitative data analysis software and hence iterative process in stage (iii) to identify and categorize the themes were analysed. Interestingly, all these analytical processes were interrelated in that the researchers in this study were constantly switching among the aforementioned activities throughout the analysis prior the data display and data conclusion verifications could be made (30).

RESULTS

The samples comprised of 19 recurrent HF patients (14 males and 5 females) who have provided informed consent for the interviews (Table II). Their mean age was 61 years as in Table II. Gender and race could not be balanced in light of the difficulty in obtaining patients who fulfilled the inclusion criteria.

Four themes – physical, psychological, social, and spiritual well-being – emerged from the data. There was evidence of the presence of constructs or sub-themes that contributed to each theme. Table III summarizes the key themes and their respective sub-themes.

Physical Well-being

Six sub-themes or constructs contributed to a person's physical well-being. These included physical functionality, fatigue, sleep problems, dietary changes, lifestyle-related difficulties, and self-care behaviours. Ten informants reported that symptoms like fatigue restricted their physical functionality. For example, they had difficulty in walking around their homes and climbing stairs, apart from being unable to engage in sports activities.

“When I go for a walk, I feel tired. This is troublesome. Previously, I could climb stairs, but recently, I couldn't because of shortness of breath. My doctor has informed me that I can walk now. However, for the past month, I couldn't walk at all”. (Informant 1)

“I have no energy and I have to hold on to everything

Table II: Demographic characteristics of participants

ID	Ethnicity	Age	Gender	Marital Status	Hospitalization Status	*New York Heart Association (NYHA) Classification
1	Indian	82	Male	Married	Inpatient	NYHA III
2	Malay	65	Male	Married	Inpatient	NYHA I
3	Malay	55	Male	Married	Outpatient	NYHA II
4	Malay	80	Male	Married	Inpatient	NYHA II
5	Indian	62	Male	Married	Inpatient	NYHA I
6	Malay	60	Female	Married	Inpatient	NYHA I
7	Malay	39	Male	Single	Inpatient	NYHA I
8	Malay	74	Male	Single	Inpatient	NYHA II
9	Malay	40	Female	Married	Inpatient	NYHA I
10	Chinese	42	Male	Single	Inpatient	NYHA I
11	Malay	59	Female	Married	Inpatient	NYHA II
12	Indian	73	Female	Widow	Inpatient	NYHA II
13	Malay	59	Male	Married	Outpatient	NYHA I
14	Indian	62	Male	Married	Inpatient	NYHA II
15	Malay	55	Male	Married	Outpatient	NYHA I
16	Malay	65	Male	Married	Inpatient	NYHA II
17	Chinese	72	Male	Married	Inpatient	NYHA III
18	Malay	61	Male	Married	Inpatient	NYHA I
19	Malay	75	Female	Married	Inpatient	NYHA II

*NYHA I (No symptoms and no limitation in ordinary physical activity), NYHA II (Mild symptoms and slight limitation during ordinary activity), NYHA III (Significant limitation in activity due to symptoms), NYHA IV (Severe limitations, and symptoms persists even at rest)

nearby when I walk; maybe because my energy has decreased. When I'm going down the stairs, I couldn't move fast; I had to take one step at a time”. (Informant 14)

All informants reported sleep difficulties, especially at night. Fourteen of them clarified that this was due to breathing difficulties.

“I could sleep well since I came to the hospital. For the past three weeks, I couldn't sleep because my breathing problems were very disturbing”. (Informant 8)

Also, four of the informants claimed that HF led to major changes in their dietary intake as they were no longer able to enjoy their favourite food and had to carefully select their food (e.g. oily foods had to be avoided).

“My wife restricted everything in my food; sometimes this made me angry. However, I am currently adjusting to my new diet. It takes around 2 to 3 months to acclimatise. When I was angry, she would say that she was only following the doctor's advice. After a while, I got used to it”. (Informant 1)

Lifestyle limitations were reported as well. For instance,

Table III: Key themes and sub-theme representations of overall patient’s perception towards their quality of life

Themes	Sub-themes	In Vivo Coding	Transcripts
1. Physical Wellbeing	1.1 Symptom management	Charts	“I want to know my blood pressure readings every time the doctors come to see me. For my own interest, I have created charts for my blood pressure and uric acid readings. I can see how they change”. (Informants 4)
	1.2 Physical functionality	Bathing	Now I can do my own bathing but last week I can’t do anything. I feel tired at time. But since I come here (hospital) I can. (Informant 2)
	1.3 Fatigue	Tired	“When I go for a walk, I feel tired . This is troublesome. Previously, I could climb stairs, but recently, I couldn’t because of shortness of breath. My doctor has informed me that I can walk now. However, for the past month, I couldn’t walk at all”. (Informant 1)
	1.4 Sleeping Problems	Could not sleep	“I could sleep well since I came to the hospital. For the past three weeks, I couldn’t sleep because my breathing problems were very disturbing”. (Informant 8)
	1.5 Dietary Changes	Diet	“My wife restricted everything in my food; sometimes this made me angry. However, I am currently adjusting to my new diet . It takes around 2 to 3 months to acclimatise. When I was angry, she would say that she was only following the doctor’s advice. After a while, I got used to it”. (Informant 1)
	1.6 Lifestyle difficulties	Routine Activities	“Previously, I was very active in activities like visiting family members and friends, outings, cooking, gardening, and going for dinners with my closest ones. However, for the past four weeks, I was no longer able to do all that”. (Informant 6)
2. Psychological Wellbeing	2.1 Sad, depression and hopelessness	Sad	I’m quite sad . I’m having an illness and I can’t help my family financially. Most of the time I felt really sad like nobody can make me happy. Sometimes I don’t know what actually made me sad and easily crying (Informant 9)
		Depressed	I have difficulty in going out and celebrating parties, unlike the time when I did not have this disease. I prefer to be alone; I think I’m depressed . (Informant 7)
	2.2 Anxiety	Worried	“Sometimes, I’m worried about my illness and also my children. I’ve been thinking a lot about my children. They are still young and have not even reached 10 years old, but I’m already ill”. (Informant 9)
	2.3 Hope and Optimism	Healthy	“Of course, I want to be healthy . I want to get well. I really want to get well. I want to live as healthily as others do, and I wanted to do all activities that I’ve planned to do! There are still many things that I want to do”. (Informant 3)
	2.4 Fear	Scared	“I get short of breath, especially when I walk. Suddenly, I became weak. I was very scared during such times since I felt that my health condition was worsening”. (Informant 1)
	2.5 Cognitive and attention disturbance	Thoughts flooding	“I can’t drive because when I drive, my mind is always disturbed. I get sick due to the heart problems so I go deep into my own thoughts . There is no happiness. My mind keeps getting fuzzy; there is no peace, and everything is uncertain”. (Informant 5)
3. Social Wellbeing	3.1 Family and Friend Relationship	Wife	“Before this, I split the household chores with my wife , like paying the bills, going to the market... but, now she does everything, especially when I fell ill or was hospitalized”. (Informant 3)
	3.2 Difficulties in Intimacy	Sexual intercourse	“I can’t have sexual intercourse with my wife like before”. (Informant 2)
	3.3 Financial Constraints	Financial support	I’m no more working, I don’t have money, and currently I’m hoping a financial support from my children. Actually they are the one who not allow me to work; they said I no need to sell foods at the stall. (Informant 12)
4. Spiritual Wellbeing	4.1 Spiritual Beliefs	God	“If God gives us illness, it’s not because God don’t love us, there is wisdom for everything that happens to us. God wants to clean our sins”. (Participant 15)
	4.2 Religious practice	Practices	“I pray to stay positive. I practise ‘fa lun gong’; it’s similar to Tai Chi... it’s an exercise which taps into our spiritual energy and is derived from the ‘Vajrayana’ branch of Buddhism. ‘Da fa’ is the principle of truth. Through these exercises, I’ve become kinder and more patient”. (Informant 17)
	4.3 Beliefs on Traditional or alternative rituals	Traditional medicine	“The doctors and nurses asked me to eat these medications. It’s nonsensical! Do you think my illness is caused by scientific reasons? Actually, the cause of my illnesses is black magic ! I did try for traditional medicine .. but from the outcome will be the same.. they said that I’ve been possessed by <i>santau</i> (black magic). (Informant 16)

the informants did not have the capacity to perform outdoor activities – including going on holiday, visiting friends, travelling, and shopping. They lamented the loss of quality time with their family members and the decrease in enjoyment in their activities. Seven of the informants expressed disappointment over their dependence on others or need for help from family members.

“Previously, I was very active in activities like visiting family members and friends, outings, cooking, gardening, and going for dinners with my closest ones.

However, for the past four weeks, I was no longer able to do all that”. (Informant 6)

The methods of HF symptom management were identified through the patients’ efforts to adapt to their illnesses. Seven of them mentioned that the initial changes in their self-care behaviour were frustrating. However, with sufficient practice of these strategies with guidance from their health professionals, they were able to acclimatize to the new measures like fluid intake monitoring, adherence to medications, symptom evaluation, performance of moderately-vigorous

activities, making adjustments as per the prescribed medical therapy, and execution of chart-based self-monitoring of blood pressure or uric acid levels.

"I want to know my blood pressure readings every time the doctors come to see me. For my own interest, I have created charts for my blood pressure and uric acid readings. I can see how they change". (Informants 4)

Psychological Well-being

The informants described their negative emotions after being diagnosed with HF. These emotional and psychological changes were important indicators of their levels of psychological well-being and positive handling of the illness. There were six sub-themes here – i) sadness, depression, and hopelessness; ii) anxiety; iii) hope and optimism; iv) fear; v) cognitive and attention disturbance; as well as vi) anger – all of which were attributes of psychological well-being. Evidently, sadness or unhappiness were commonly reported by the HF patients.

"I have difficulty in going out and celebrating parties, unlike the time when I did not have this disease. I prefer to be alone; I think I'm depressed". (Informant 7)

Six of the informants also claimed that they felt hopeless as they could no longer perform physical activities. Oftentimes, they experienced despair to the point of tearfulness.

"I became lazier; I feel that there's no more hope for me". (Informant 11)

Additionally, ten of them also reported were anxious over the impact of the symptoms of HF as well.

"Now, I'm afraid when people are around me. Before this, I always went around, meeting my friends; I often saw them. Now that I'm not working, I refuse to see them. I don't want them to ask me how and what I'm doing". (Informant 10)

Seven of them constantly worried over their responsibilities (especially those towards their families) and loss of quality time spent with their closest ones.

"Sometimes, I'm worried about my illness and also my children. I've been thinking a lot about my children. They are still young and have not even reached 10 years old, but I'm already ill". (Informant 9)

Seven informants were fearful of their symptom(s) of HF and its adverse impact on their physical health as well as future responsibilities.

"I get short of breath, especially when I walk. Suddenly, I became weak. I was very scared during such times since I felt that my health condition was worsening".

(Informant 1)

"I'm quite afraid because both of my children are still unmarried. What I remembered since I had this illness was that my children have not settled down. That's why I'm afraid of my future". (Informant 12)

These mixed feelings – which were predominantly accounted for by the patients' uncertainties of their futures – ultimately led to anger.

"Yes, I feel angry... why do I have this illness at this time? I still have small children. Why? Why I'm the one who has to suffer from this disease? Why not other people?" (Informant 9)

Furthermore, two respondents reported cognitive and attention disturbances. Specifically, they were unable to concentrate, even during the performance of routine activities. Also, their minds were never relaxed because they perceived everything to be uncertain after being diagnosed with HF.

"I can't drive because when I drive, my mind is always disturbed. I get sick due to the heart problems so I go deep into my own thoughts. There is no happiness. My mind keeps getting fuzzy; there is no peace, and everything is uncertain". (Informant 5)

However, an increase in the QOL of the HF patients appeared to coincide with hope and optimism. Five of the informants claimed that they were optimistic in the performance and resumption of their routine activities, even though they knew that the underlying disease could not be cured.

"Of course, I want to be healthy. I want to get well. I really want to get well. I want to live as healthily as others do, and I wanted to do all activities that I've planned to do! There are still many things that I want to do". (Informant 3)

Social Well-being

Social well-being comprised three sub-themes: i) relationships with family and friends, ii) difficulties in intimate relationships, and iii) financial constraints. Seven of the patients felt that they were a burden to their families since they had lost their ability to perform tasks like household chores, cooking, and going to the market on their own; these chores frequently had to be taken over by their spouses or children.

"Before this, I split the household chores with my wife, like paying the bills, going to the market... but, now she does everything, especially when I fell ill or was hospitalized". (Informant 3)

Financial constraints were another major issue owing to the patients' inability to go to work, so they needed

monetary assistance from their families and significant others. Two patients reported that their jobs have been adversely affected after they had the illness. One of them stated that he was very concerned about his family's financial status.

"My wife is working, and my daughter is studying at a college. My daughter doesn't know that I'm here. They used to visit me regularly, but since I had to stay here for such long time, they no longer came to see me. My wife has to work hard for my daughter's education". (Informant 5)

Furthermore, three patients claimed that their intimate and marital relationships were took a significant downturn in view of HF.

"I can't have sexual intercourse with my wife like before". (Informant 2)

Spiritual Well-being

HF patients of multiple ethnicities had differing perceptions towards the link between their illness and religious or spiritual beliefs. Hence, spiritual well-being played a crucial role in the QOL of patients. It was a new theme in this study, and its three sub-themes were spiritual beliefs, religious practices, and beliefs towards traditional or alternative rituals. As per the informants' spiritual beliefs, HF was a gift from God which could absolve their previous sins. With this perception, they were able to view the disease in a positive manner. One of the patients mentioned that it was important for them to believe in God's power so that they would be motivated to accept their illness and finally get closer to God. However, three patients believed that the disease was a punishment or karma handed down by God.

"If God gives us illness, it's not because God don't love us, there is wisdom for everything that happens to us. God wants to clean our sins". (Informant 15)

In addition, five informants believed that the disease was their destiny. Even though they are suffering from HF, they still performed their religious practices in accordance to their beliefs. They were also of the view that apart from modern treatment modalities, alternative ones like prayers, rituals, traditional meditations, and yoga could improve their QOL.

"After 'fajr' [which meant 'dawn' in the Arabic] prayers, we recite the Holy Qur'an. This is my pillar of strength. Praying is important, and that includes any form of prayer from our Prophet and his companions. We memorise and recite the prayers. For example, 'shifa' is a mantra for wellness". (Informant 16)

"I pray to stay positive. I practise 'fa lun gong'; it's similar to Tai Chi... it's an exercise which taps into our spiritual energy and is derived from the 'Vajrayana' branch of

Buddhism. 'Da fa' is the principle of truth. Through these exercises, I've become kinder and more patient". (Informant 17)

Interestingly, some of the patients believed that traditional or alternative rituals were important to dispel the evil spirits that were disturbing them and hence, improve their well-being.

"When these evil spirits come to us... they don't allow us to live normally like others. They will make us suffer! You'll shout, you're easily angered... and you become insane! During my admission, I was unconscious... I talked nonsense, the nurse said I talked nonsense; I couldn't control myself because I could feel large hands suffocating me! The hands didn't allow me to breathe; they shut off my nose and mouth". (Informant 3)

Furthermore, two patients mentioned that they have sought for advice from shamans because they believed that the illness was caused by black magic.

"The doctors and nurses asked me to eat these medications. It's nonsensical! Do you think my illness is caused by scientific reasons? Actually, the cause of my illnesses is black magic!" (Informant 16)

DISCUSSION

This qualitative study has identified the key themes and sub-themes of the QOL of heart patients in multi-ethnic Malaysia. These findings are concurrent with the reviews of Western HF patients' QOL (31). Many past studies have found similar physical and psychosocial deficits in the health-related QOL of HF patients (32). HF not only negatively affected a patient's physical routines; it also restricted the patients' ability to function independently, often leading to psychosocial impairments. This research has found a prominent spiritual and cultural influence on the QOL of Malaysian HF patients, which has not been noted in the Western context.

With reference to the qualitative analysis, the HF patients had difficulties in their physical functionality. Some of the coping methods that have been successfully adopted were i) dietary modifications as recommended by health professionals, ii) sleep position adjustments in the event of sleep difficulties, iii) adherence to treatment and medications, iv) monitoring of fluid intake, v) evaluation of symptoms, and vi) performance of moderately-vigorous activities. As per the respondents' feedback, symptomatic management of HF have been shown to be able to improve their QOL. Exercise or physical activity, in particular, is well-known to be an effective intervention to reduce depression in Parikh., K et al. (33) and capable to enhance the QOL (34) of HF patients. Symptoms of HF like breathlessness (35) and fatigue (14) – as reported by the respondents – reduce self-esteem and create fear of engaging in physical activities. These

limitations result in the feeling of physical hopelessness in the patients, as well as their dependence on social support (34). However, patient education by health professionals on topics like postural adjustments for sleeping difficulties, importance of compliance with medications, and selection of proper diets have helped the former to cope with their symptoms. This concurred with previous Malaysian reports on the benefits of educational interventions in patient self-management strategies (14).

It is important to educate patients on self-care during the early stages of the disease, apart from prescribing medications and lifestyle changes (36). Unfortunately, the majority of the patients in this study were not aware of the importance of symptomatic management of HF when they were treated at public primary hospitals over the past few years; they were only educated on the same when they were referred to the tertiary hospital. In Malaysia, comprehensive health resources have been established at semi-private tertiary hospitals with the specific aim of educating and encouraging self-management in HF patients. However, this facility is not available in the district or primary public health care settings owing to the heavy financial requirements. Thus, people from the lower income groups were at a disadvantage. Hence, it is important to realign all healthcare systems in Malaysia by adopting strategies that have been shown to be cost-effective for public settings. More congruent elements like social support, as well as proper cultural and healthcare environments should be made available in low- and middle-income countries (37). For instance, the integration of peer and family support can lessen the burden on costly healthcare resources (38).

From the qualitative perspective of psychological well-being, the respondents were emotionally disturbed during their initial adjustments to HF, whereby the main problem was limitation in physical functionality. Uncertainty about the future, anger, and bereavement were some of the stages of psychological adjustments in the HF patients (39); these were evident in the interviews, especially for those who reported feelings of depression and hopelessness. The reasons for the negative emotions were the perceived impairments in their role and function within their families, as well as the inability to fulfill their family-related responsibilities (40). In contrast, a few informants accepted the disease better through social support and spirituality practices (41).

The patients in this study have highlighted the importance of family and peer support in the enhancement of QOL and the ability to cope with the illness positively. Similarly, HF had an effect on the patients' interpersonal relationships which include intimacy, marital relationships, and financial constraints (42). Social support plays an important role

in treatment adherence among heart failure patients. Systematic reviews suggest several improvements with social support such as low sodium diet, better self-care maintenance, and participation in physical activity (43), and also predicted improved health-related QOL (44). Patient's assumption on the burden perceived by their caregiver was reported in this study, even though contrary from previous study that suggest the caregiver contribution to heart failure self-care enhances patient outcomes and not burdensome for caregivers (45). Furthermore, in agreement with previous studies, most of the respondents here have also commented on financial limitations since they perceived that their illness resulted in a higher risk of job loss, extra travel expenses to the hospital, and inability to support their families in which also consequent on their treatment adherence (46). These financial restrictions burden their caregiver and cause continuous debilitating issues that can lead to self-blame and psychological disturbances the patients, which in turn give rise to poor QOL (43). Thus, there is a need for the healthcare providers to take these issues into consideration and come up with tailored social support-education interventions which can help the patients and their social support to achieve better self-care management (46).

Spirituality is one of the crucial factors that can help multi-racial HF patients adapt to the progressive burden of the disease (41). This is in spite of the different interpretations of the meaning of the illness (i.e. either a gift to get closer to God or as punishment from God to cleanse their previous sins). This strong submission to a higher power with the aim to achieve a peaceful death improves the patients' positive inner strength and hence, QOL. This study revealed spirituality as a commonly shared factor between all major ethnic groups in Malaysia of different religions such as Islam and Buddhism. Reaching out to God through religious practices, and positive coping mechanisms from their religious beliefs while adjusting with their illness help to achieve better QOL. Similarly with this study, other studies also indicate that spirituality assists patients in facing their life's stressful circumstances through rituals and praying for better health and inner strength to be able accept their illness positively, which provide them strength and hope (47). Few studies have focused on spiritually supported patients as compare to those without support. This awareness of being spiritually engaged for health could foster a feeling of spiritual support, better illness resilience, enhance the patient's ability to cope with their illness symptoms, and consequently increase meaningful experience of their physical health related QOL (48).

Similarly, studies with South Asian perspectives reported that despite coming from different Asian ethnicities, patients who had stronger spiritual beliefs were more optimistic and philosophical towards their future (41), and associated collectivist culture have beneficial

impact on the patient's health and functioning (49). Nevertheless, in this study cultural issues were also evident since some patients, particularly Malays, did not take their prescribed medications regularly in light of their belief that the illness is due to supernatural causes. This staunch belief often led to unhealthy lifestyles, such as the overconsumption of oily foods. Hence, it is important for the health professionals to understand and familiarize themselves with the aforementioned cross-cultural issues in the patients so as to overcome these barriers to medical adherence (13, 14, 16, 17). Accordingly, it has been suggested the patients' perceptions of their illnesses should be handled with reference to Malaysia's collectivistic culture (38).

As the study was conducted at a tertiary referral centre, the sampled HF patients might not have represented the typical HF population seen by general practitioners. Furthermore, owing to the limited research period, the feedback from the three ethnic groups were analysed together to summarise the important factors and hence, facilitate the establishment of interventions that were applicable to all races. Nevertheless, there were more Malays in this study, which was compatible with the fact that Malays are the predominant ethnic group while the Chinese and Indians minority ethnic groups in Malaysia. Additionally, the presence of more male patients here also agreed with the male preponderance of heart disease.

CONCLUSION

Multi-ethnicity, cross-cultural issues, and quality of life (QOL) are important determinants of the success of medical self-management in Malaysia. Also, the symptoms of heart failure (HF) have an impact on four main domains of patient QOL: physical, psychological, spiritual, and social well-being. Most HF patients in Malaysia are only admitted into tertiary hospitals when their illness is severe; this might explain the poor receptivity of the prescribed self-care measures. The lack of appropriate cardiac rehabilitative methods is accentuated by the fact that most patients who are in the early stages of the illness will not be provided with HF symptom-management interventions at the primary hospitals. Furthermore, patient-related psychological factors like anger and hopelessness are rarely discussed by the health professionals even though the patients are significantly affected by the same.

This study shows that spirituality and strong support systems are recommended for the improvement of QOL in HF patients. Furthermore, cultural beliefs in supernatural elements might have an effect on the adherence to therapy, so it needs to be regarded as a barrier to the aforementioned compliance. Since Malaysia is also known for its collectivistic culture, family and peer support can help improve self-care and adherence to medications. According to the respondents'

feedback, poorer interpersonal relationships are likely to arise from financial issues. In view of the fact that the important factors in this qualitative analysis did not fully agree with Western models of the same, and that there was insufficient access to appropriate treatment modalities, there is an urgent need to come up with innovative strategies to modify the current methods of management to benefit all Malaysians with HF.

ACKNOWLEDGEMENTS

The authors would like to extend their gratitude to the Research Management and Innovation Centre (RMIC), Sultan Idris Education University (UPSI) for the University Research Grants (Code: 2017-0135-106-01) that helped fund the research.

REFERENCES

1. Prabhakaran D, Jeemon P, Sharma M, Roth G, Johnson C, Harikrishnan S, et al. The changing patterns of cardiovascular diseases and their risk factors in the states of India: The global burden of disease study 1990–2016. *The Lancet Global Health*. 2018;6(12):e1339-e1351. doi:10.1016/s2214-109x(18)30407-8.
2. Savarese G, & Lund L. Global Public Health Burden of Heart Failure. *Cardiac Failure Review*. 2017;03(01):7. doi:10.15420/cfr.2016:25:2
3. Lam SP. Heart failure in Southeast Asia: facts and numbers. *ESC Heart Fail*. 2015;2(2):46-49.
4. Teh BT, Lim MN, Robiah A, et al. Heart failure hospitalizations in Malaysia. *J Card Fail*. 1999;5(3):64.
5. Chong AY, Rajaratnam R, Hussein NR, Lip GYH. Heart failure in multi-ethnic population in Kuala Lumpur, Malaysia. *Eur J Heart Fail*. 2003;5(4):569-574.
6. Ministry of Health Malaysia. Clinical practice guidelines management of heart failure. <http://www.moh.gov.my/penerbitan/CPG/Management%20of%20Heart%20Failure%202nd%20Edition.pdf>. Accessed July 13, 2018.
7. Adebayo SO, Olunuga TO, Durodola A, Ogah OS. Quality of life in heart failure: a review. *Nig J Cardiol*. 2017;14(1):1-8.
8. Poorshadan, S., Fallahi, M., Abdi, A., Mahdavi, S., Miri, J. and Azami, H. Quality of Life and its Predictors in Hospitalized Patients with Heart Failure at Hospitals Affiliated to Kermanshah-Iran University of Medical Sciences. *J Cardiovasc Disease Res*. 2019;10(1):16-19.
9. Farmakis, D., Stafylas, P., Giamouzis, G., Maniadakis, N. and Parissis, J. The medical and socioeconomic burden of heart failure: A comparative delineation with cancer. *International Journal of Cardiology*. 2016; 203:279-281.
10. Seah, A., Tan, K., Huang Gan, J. and Wang, W. Experiences of Patients Living With Heart Failure.

- Journal of Transcultural Nursing. 2015; 27(4):392-399.
11. Whitehead L, Jacob E, Towell A, Abu-qamar M, Cole-Heath A. The role of the family in supporting the self-management of chronic conditions: A qualitative systematic review. *Journal of Clinical Nursing*. 2017;27(1-2):22-30. doi:10.1111/jocn.13775
 12. Freund T, Wensing M, Mahler C, et al. Development of a primary care-based complex care management intervention for chronically ill patients at high risk for hospitalization: a study protocol. *Implement Sci*. 2010;5:70.
 13. Lee WL, Abdullah KL, Bulgiba AM, Abidin IZ. Prevalence and predictors of patient adherence to health recommendations after acute coronary syndrome: data for targeted interventions? *European Journal of Cardiovascular Nursing*. 2013;12(6):512-20. doi:10.1177/1474515112470056.
 14. Ming LC, Hassali MA, Shafie AA, Awaisu A, Hadi MA, Al-Haddad M. Perspectives of heart failure patients in Malaysia towards medication and disease state management: findings from a qualitative study. *J Public Health*. 2011;19(6):569-577.
 15. Walthall, H., Jenkinson, C. and Boulton, M. Living with breathlessness in chronic heart failure: a qualitative study. *Journal of Clinical Nursing*, 2017;26(13-14):2036-2044.
 16. Sun XG. Rehabilitation practice patterns for patients with heart failure: The Asian perspective. *Heart Fail. Clin*. 2015; 11: 95–104. doi: 10.1016/j.hfc.2014.09.001.
 17. Choo, C., Chew, P., Lai, S., Soo, S., Ho, C., Ho, R. and Wong, R. Effect Of Cardiac Rehabilitation On Quality Of Life, Depression And Anxiety In Asian Patients. *International Journal of Environmental Research and Public Health*. 2018;15(6):1095. doi:10.3390/ijerph15061095
 18. Willig C. *Introducing qualitative research in psychology*. UK: McGraw-Hill International: 2013.
 19. Smith, J.A. (2nd Ed.). *Qualitative psychology: A practical guide to research methods*. Sage Publication; 2015.
 20. Miles, M. B., & Huberman, A. M. *Qualitative data analysis: An expanded sourcebook*, 2nd ed. Thousand Oaks, CA, US: Sage Publications, Inc; 1994.
 21. Moser A, Korstjens I. Series: Practical guidance to qualitative research. Part 3: Sampling, data collection and analysis. *European Journal of General Practice*. 2018;24(1): 9-18. doi:10.1080/13814788.2017.1375091.
 22. Rector TS, Cohn JN. *Minnesota living with heart failure questionnaire*. Minnesota, MN: University of Minnesota; 2004.
 23. Ming L, Hassali M, Shafie A, Awaisu A, Hadi M, Al-Haddad M. Perspectives of heart failure patients in Malaysia towards medications and disease state management: findings from a qualitative study. *Journal of Public Health*, 2011;19(6): 569-577. doi:10.1007/s10389-011-0415-5.
 24. Brocki JM, Wearden AJ. A critical evaluation of the use of Interpretative Phenomenological Analysis (IPA) in Health Psychology. *Psychol and Health*. 2006;21(1):87-108.
 25. Barbour, R. S. (2001). Checklists for improving rigour in qualitative research: a case of the tail wagging the dog? *Bmj*, 322(7294), 1115–1117.
 26. Creswell, J. W. (2014). *A concise introduction to mixed methods research*. Sage Publications.
 27. Ministry of Health. *Clinical practice guidelines – cardiovascular*. Ministry of Health. 2007 [cited 2019 February 06] Retrieved from <http://www.moh.gov.my/index.php/pages/view/133>.
 28. Smith JA, Flowers P, Larkin M. *Interpretative phenomenological analysis: theory, method and research*. UK: Sage: 2009.
 29. Merriam SB. *Qualitative research: a guide to design and implementation*. New Jersey, NJ: John Wiley and Sons; 2015.
 30. Braun V, Clarke V, Terry G, Rohleder P, Lyons A. *Thematic Analysis*. In: *Qualitative Research in Clinical and Health Psychology*. Basingstoke: Palgrave Macmillan; 2014:95.
 31. Jeon YH, Kraus SG, Jowser T, Glasgow NJ. The experience of living with chronic heart failure: a narrative review of qualitative studies [published online March 24, 2010]. *BMC Health Serv Res*. doi: 10.1186/1472-6963-10-77.
 32. Sokoreli I, de Vries J, Pauws S, Steyerberg E. Depression and anxiety as predictors of mortality among heart failure patients: systematic review and meta-analysis. *Heart Failure Reviews*. 2015;21(1):49-63. doi:10.1007/s10741-015-9517-4
 33. Parikh K, Coles A, Schulte P, Kraus W, Fleg J, Keteyian S, et al. Relation of Angina Pectoris to Outcomes, Quality of Life, and Response to Exercise Training in Patients With Chronic Heart Failure (from HF-ACTION). *The American Journal of Cardiology*. 2016;118(8):211-216. doi:10.1016/j.amjcard.2016.07.040
 34. Mohamed NF, Azan A, Peterson RF, Alwi MN, Shaharom MH. Mental and physical health comparison among psychologically distressed heart failure patients in Malaysia. *Procedia Soc Behav Sci*. 2014;127:412-416.
 35. Asano R, Mathai S, Macdonald P, Newton P, Currow D, Phillips J, et al. Oxygen use in chronic heart failure to relieve breathlessness: A systematic review. *Heart Failure Reviews*. 2019. doi:10.1007/s10741-019-09814-0.
 36. Boyde M, Peters R, New N, Hwang R, Ha T, Koczyk D. Self-care educational intervention to reduce hospitalisations in heart failure: A randomised controlled trial. *European Journal of Cardiovascular Nursing*. 2017;17(2):178-185.

- doi:10.1177/1474515117727740
37. Netto G, Bhopal R, Lederle N, Khatoon J, Jackson A. How can health promotion interventions be adapted for minority ethnic communities? Five principles for guiding the development of behavioural intentions. *Health Promo Int.* 2010;25(2):248-257.
 38. Yasin S, Chan CKY, Reidpath DD, Allotey P. Contextualizing chronicity: a perspective from Malaysia. *Global Health.* 2012;8:4.
 39. Ridder D, Geenen R, Kuijjer, R, van Middendorp H. Psychological adjustment to chronic disease. *Lancet.* 2008;372(9634):246-255.
 40. Nicholas Dionne-Odom J, Hooker S, Bekelman D, Ejem D, McGhan G, Kitko L, et al. Family caregiving for persons with heart failure at the intersection of heart failure and palliative care: a state-of-the-science review. *Heart Failure Reviews.* 2017;22(5):543-557. doi:10.1007/s10741-017-9597-4.
 41. Mohamed NF, Azan A, Lebar O, Shaharom MH, Peterson RF. Family support, positive thinking and spirituality correlates on psychologically distressed heart failure patients. *Procedia Soc Behav Sci.* 2014;127:484-488.
 42. Hammash MH, Crawford T, Shawler C, Schrader M, Lin CY, Shewekah D, Moser DK. Beyond social support: Self-care confidence is key for adherence in patients with heart failure. *European Journal of Cardiovascular Nursing.* 2017;16(7):632-637. doi: 10.1177/1474515117705939.
 43. Pattenden JF, Roberts H, Lewin RJP. Living with heart failure: patient and carer perspectives. *Eur J Cardiovasc Nurs.* 2007;6(4):273-279.
 44. Philippou, K., Lambrinou, E., Ktisti, S., Kyriakou, M. and Middleton, N. (2019). Social support and adherence to the therapy in patients with heart failure: a systematic review. Wiley-Blackwell.
 45. Durante, A., Greco, A., Annoni, A., Steca, P., Alvaro, R. and Vellone, E. Determinants of caregiver burden in heart failure: does caregiver contribution to heart failure patient self-care increase caregiver burden?. *European Journal of Cardiovascular Nursing,* 2019; <https://doi.org/10.1177%2F1474515119863173>.
 46. Greaves, C., Wingham, J., Deighan, C., Doherty, P., Elliott, J., Armitage, W., Clark, M., Austin, J., Abraham, C., Frost, J., Singh, S., Jolly, K., Paul, K., Taylor, L., Buckingham, S., Davis, R., Dalal, H. and Taylor, R. Optimising self-care support for people with heart failure and their caregivers: development of the Rehabilitation Enablement in Chronic Heart Failure (REACH-HF) intervention using intervention mapping. *Pilot and Feasibility Studies,* 2016: 2(1). <https://doi.org/10.1186/s40814-016-0075-x>.
 47. Jors K, Bissing A, Hvidt NC, Baumann K. Personal prayer in patients dealing with chronic illness: a review of the research literature. *Evid Based Complement Alternat Med.* 2015 :927-973.
 48. Abu, H., McManus, D., Lessard, D., Kiefe, C. and Goldberg, R. (2019). Religious practices and changes in health-related quality of life after hospital discharge for an acute coronary syndrome. *Health and Quality of Life Outcomes.* 2019; 17(1).
 49. Singh, K., Junnarkar, M., Singh, D. et al. *J Relig Health.* 2019. <https://doi.org/10.1007/s10943-019-00877-9>.