

## Exploring the Lived Experience of Congestive Heart Failure Patients in Bulukumba Regency, Indonesia

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### ABSTRACT

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Congestive Heart Failure has become a major problem in the society worldwide with high prevalence, high mortality and morbidity, resulting in huge financing for care, carrying such a large burden on patients. In Indonesia, congestive heart failure has become one of the main killers. The prevalence of heart disease in Indonesia from year to year is increasing. Patients with CHF generally have various health problems, functional physical limitations, as well as behavioural and psychological symptoms that affect daily life and a long-term prognosis. The impact of heart failure on patients provides its own experience for sufferers. Therefore, CHF sufferers need sufficient coping to deal with the condition. This can certainly be obtained from a good support system as well, including family support as a care provider at home. To date, research that explores coping and family support specifically for people with heart failure and in-depth exploration of the experiences of people with CHF, especially in Bulukumba regency, has been limited. This study aims at exploring the experience of CHF patients in living their daily lives. This study used a qualitative approach with phenomenology design. The study had been conducted throughout September – October 2018. Using purposive sampling technique, three outpatient individuals with CHF was interviewed and the data was analysed by employing thematic analysis. The findings highlight three themes, including feeling after diagnosed with CHF, coping mechanism, and the importance of family support. This study suggest that approach towards providing health services to individuals with CHF should incorporate patient's experience-based interventions to support their therapy adherence and to improve their quality of life.

**Keywords:** Congestive heart failure, patient experience, feelings, coping, and family support

### INTRODUCTION

Heart failure, known as Congestive Heart Failure or CHF, is still a major problem in the field of cardiology which has the highest prevalence in society. CHF plays a major role in high mortality and morbidity and results in huge financing for care, carrying such a large burden on patients and society (van Riet et al., 2016). CHF, which in several

geographical areas around the world, is suffered by many patients over 60 years of age, and this has an impact on the high rate of hospitalization (Baert et al., 2018; Duhamel, Dupuis, Reidy, & Nadon, 2007; Maggioni et al., 2016; Shahriari, Ahmadi, Babaei, Mehrabi, & Sadeghi, 2013).

Globally, the prevalence of congestive heart failure disease varies. In Australia, the proportion of CHF sufferers is between 1-2% of the total population (Sahle, Owen, Mutowo, Krum, & Reid, 2016). In America, about 5.7 million people (2.2% of the population) aged  $\geq 20$  years suffer from heart failure (Rajadurai et al., 2017). Other data from WHO states that about 3000 Americans suffer from CHF, of which about 55.3% of patients die from CHF. In Asia, although there have been no studies showing prevalence regionally (at the Asian level) (Sato, 2015; Shimokawa, Miura, Nochioka, & Sakata, 2015), the prevalence of CHF ranges from 1.2%-6.7% (Sato, 2015), and shows a tendency to become more serious as the ageing population in some Asian countries, when compared to the western world (Shimokawa et al., 2015).

In Indonesia, congestive heart failure has become one of the main killers. The prevalence of heart disease in Indonesia from year to year is increasing. According to the Basic Health Research (Riskesdas-Riset Kesehatan Dasar) in 2018, the prevalence of heart disease including congestive heart failure in Indonesia based on a doctor's diagnosis is 1.5% or approximately 1,017,290 inhabitants (Indonesia's Ministry of Health, 2019). South Sulawesi Province placed fifth in the number of hospitalized CHF patients in Indonesia, accounting for approximately 3000-4000 cases (Indonesia's Ministry of Health, 2017). In Bulukumba regency, in the period of visit January to June 2018, there were 680 patients that came to Cardiac Clinic of Outpatient Unit in the Bulukumba Public Hospital, consisting 364 male patients and 316 female patients.

Patients with CHF generally have various health problems, functional physical limitations, as well as behavioral and psychological symptoms that affect daily life and a long-term prognosis (Grigorovich et al., 2017). Most patients with heart failure often feel anxious, frightened and depressed. Almost all patients realize that the heart is an important organ and when the heart begins to break down then health is also threatened. As the disease is progressing and its manifestations is worsening, patients often have an excessive fear of permanent disability and death. The patients express fear in various

ways such as nightmares, insomnia, acute anxiety, depression and deny reality (Black & Hawks, 2014).

The impact of heart failure on patients provides its own experience for sufferers. Therefore, CHF sufferers need sufficient coping to deal with the condition. This can certainly be obtained from a good support system as well, including family support as a care provider at home (Duhamel et al., 2007; Dunbar, Gary, Clark, & Kaslow, 2008; Fry et al., 2016; Grigorovich et al., 2017; Mohamed, Azan, Lebar, Shaharom, & Peterson, 2014; Shahriari et al., 2013). Particular concern should also be given to outpatient CHF individuals as they have many obstacles, including limited times to encounter health practitioners, particularly those who live alone or lack of supports (Greene, Mentz & Felker (2018). Christensen, et al. (2019) point out that there is a firm association between feeling lonely and poor outcomes of cardiac-diagnosed patients. Besides that, association between loneliness and 1-year mortality was found in both men and women. Therefore, public health initiative related to cardiac diseases including CHF should focus on assessing loneliness as a risk factor and address the loneliness problem to prevent patients from deteriorating.

In terms of self-efficacy, a study by Hudiyawati, Ainunnisa & Riskamala (2021) involving 73 patients with heart failure found that patients could perform self-care and factors that significantly influenced it were family support and self-efficacy. The study suggests that to improve self-care among CHF patients, family support and self-efficacy are fundamental. To date, although there is a lot of scientific evidence that family support improves health behaviors and health status outcomes (Elkhateeb & Salem, 2018), in Indonesia research that explores coping and family support specifically for people with heart failure and in-depth exploration of the experiences of people with CHF has been limited or even arguably not yet a major concern. This study aims at exploring the experience of CHF patients in living their daily lives.

## **METHODS**

This study used qualitative approach with phenomenology design. The study had been conducted throughout September – October 2018. After obtaining a research permit from The Department of Research and Development of Bulukumba Regency, the research was carried out by contacting the hospital, especially in the Outpatient Installation

(Outpatient Care Policlinics) of Bulukumba Public Hospital (RSUD H. Andi Sulthan Daeng Radja) to obtain data on congestive heart failure patients.

Using purposive sampling technique, from the shortlisting of patients, researchers obtained data on a number of 13 people who met the research criteria. Of the thirteen prospective subjects of the study, three people said that they were willing to be interviewed. The characteristics of the informants of this study can be seen in the following table 1.

Table 1 : Informants' Characteristics

No	Initial	Age	Gender	Diagnosis	Occupation
1.	Mrs. N	54	Female	CHF + HHD	Household
2.	Mr. R	77	Male	CHF + HHD	Retiree
3.	Mrs. I	47	Female	CAD + CHF	Public servant

\*CHF=Congestive Heart Failure

\*HHD=Heart Hypertension Disease

\*CAD= Coronary Artery Disease

All participants went through an interview process of approximately 20-40 minutes. In-depth semi-structured interview was conducted using an interview guidelines and a recorder. To obtain research data, the results of the interview recording were carried out a transcription process by transcribing the entire conversation. After that, a process of translation, codification, and creating a theme were conducted. The process of data analysis, which in qualitative research is called Thematic Analysis, is described in the following table:

Table 2 : The process of data analysis (thematic analysis)

Stages	Name of stages	Researcher Activities
1	Familiarization of data	The researcher performed transcript readings and or re-listening to the recordings.
2	Codification	From the results of data familiarization, researchers had special codes for things that were considered important
3	Looking for themes	Researchers looked for common threads from multiple codes that were considered to have similar themes or had the same topic of discussion
4	Reviewing the themes	Researchers reviewed the themes that had been created whether they were appropriate
5	Naming the themes and providing meaning	After the themes obtained, they were reviewed repeatedly, the theme name was set
6	Writing the results	The results of the identification of the theme and the results obtained in the theme were then written to be compiled in the form of a research report.

(Nowell et al., 2017 as cited in Nurhidayah et al., 2020)

## RESULTS

The results of the above-mentioned thematic analysis are described in the table 3. The table contains the themes and each theme has its subthemes, as follows:

**Table 3 : Themes and subthemes**

Themes	Subthemes
Feelings after knowing the diagnosis	Sad after hearing the news Afraid of the worst prognosis High hope of recovery
Self-Coping Mechanism	Sincerity and resignation Obeying therapy Undertaking alternative therapy
The importance of family support	Obtaining morale support

Source: Primary Data

#### *Feelings after knowing the diagnosis*

Interviews with participants showed that they experienced various feelings when they found out they were diagnosed with CHF. This mixture of feelings includes sadness, fear, shock and anxiety to be a burden a burden for their families. Sadness when hearing from their doctors that they had CHF was expressed by all participants. This sadness was felt because they thought they would become a burden for the family and not being able to do activities as before.

*"... So, If I was brooming, ewwhh, I couldn't finish it. Sometimes, I need three times to stop and finish. I sit three times and then continue. I sweat a lot like taking shower... I came to think, I am useless, and I become a burden for my family (sobbing with teary eyes)...."* (Participant 1, 54 years old)

*".... I was sad. I felt that time that I still wanted to see my children to be successful, and I also wanted to have a grandchildren...."* (Participant 3, 47 years old)

*".... I am sad and nervous at the first place... and there has been a difference. Before this illness, I can work 100% but after that I felt only 75% of my energy..."* (Participant 2, 77years old)

Besides feeling sad after being told the diagnosis, all participants also experienced scary moments. Two participants felt that probably it was the ending time of life, and another was afraid of failing of fulfilling the religion worship, which is the ultimate goal of life.

*"... I was so scared... very scared... It was about it, I was doubt, was it my time to die. I was feeling haunted...."* (Participant 1, 54 years old)

*".... I was worried, I am afraid of the fact that I haven't worshipped optimally... I have never done hajj..."* (Participant 2, 77years old)

*".... I was a mixed feeling (laugh bitterly).. I thought about dying... mmm.. I think a lot of things..."* (Participant 3, 47 years old)

Two of the participants expressed their hopes to recover and return to normal or at least be able to reduce the impact of the disease.

*" ... I hope that I can be healthy again.. not being a burden because sometimes I think that probably, this is the time for me (to die)...."* (Participant 1, 54 years old)

*".... My wish of course to be recovered.. I want to be given a chance to see my children successful....."* (Participant 3, 47 years old)

#### *Self-Coping Mechanism*

Coping behavior that arises as a response to an event in life will differ from individuals to other individuals. In this study, coping mechanism was conveyed by participants after learning about the disease. They immediately sought help to the hospital and obediently undergo treatment, being more sincere and resigned to their current condition and all respondents sought alternative nonmedical treatment. Participants described an attitude that they were able to undertake treatment in accordance with the doctor's instructions. According to the participant's confession during the interview, they had routinely controlled and obeyed the therapy to take medications as the doctor's recommended.

*" ... Now, I do medical control (check up) every month.. actually my schedule is every one month but when I feel sick because of the disease, I will visit the heart clinic at the hospital. If I routinely check my condition and drin medicine regularly, I feel better...."* (Participant 1, 54 years old)

*".... So I now follow doctor's instruction to limit my activities. The doctor's advice was to not be too exhausted and tired, limit activities, because I wish to recover, so I obey my doctor's role, routinely consume medicine prescribed to me, and stop heavy activities ..."* (Participant 2, 77years old)

After knowing the current diagnosis and receiving doctor's advice, participants have becoming more open-minded in relation to sincerity and resignation. They accept the condition and enjoy the destiny given to them.

*" ... I was distracted by the disease because it limits my activities, but I have lived with it. I feel disturbed but can do nothing, so I accept it. I will try to make it easy...."* (Participant 1, 54 years old)

*".... This is my destiny. I had lived so powerful and passionate enough especially when I was younger. Now, I have to admit that I am old and I accept the disease..."* (Participant 2, 77years old)

*"....it will be the God Decision. I will always be praying..."* (Participant 3, 47 years old)

Non-professional services or non-medical treatment are often chosen by participants to reduce the symptoms of their illness, such as consuming herbs and vitamins that were not prescribed by their medical doctors. All participants agreed that they have undertaken alternative therapies at least once.

*“ ... Sometimes I got an information from my husband that somewhere there was an indigenous medical practitioner or shaman.. I would go visit that shaman with my husband or family or taking herbal medicine.. no, I didn't tell my doctor about it....”* (Participant 1, 54 years old)

*“.... Mmmm, I have tried alternative treatment because my children bought herbal medicine or vitamin that were not prescribed by my doctor...”* (Participant 2, 77years old)

*“.... Yes, I drink herbal liquid... I didn't consult it to the doctor (laughing)...”* (Participant 3, 47 years old)

#### *The importance of family support*

The sick individuals stated that they urgently needed support from various parties especially from their own families during difficult times. The support would help participants in carrying out their therapies, diet and treatment. Participants in this study revealed how important such supports are, especially support from family members. Sources of support can come from friends, neighbors and family. The moral support obtained by the participants in the form of motivation, attention and care provided by their family members. The most interesting thing is that all participants conveyed that even a small act of attention, for example, asking the sick person during their medication time, is considered very motivating and supportive.

*“ ... family support means a lot, it feels that I am not alone, there is someone that supports me, motivating myself so I am not distressed because of the disease.. my husband always reminds my schedule of medical check-up.. their attention is so enough that I feel so motivated....”* (Participant 1, 54 years old)

*“.... I feel that my family support is so great because when I felt unwell, they asked me what food or drink that I wanted to consume. Each of my need has always been fulfilled by my family... What I feel the most relaxing is that they do care with me, they always said that I have to limit my activities, don't be exhausted to recover my body and my family always reminds me the time to eat medicine...”* (Participant 2, 77years old)

*“.... God bless. They all (husband and three sons), their love and nurturing to me are extraordinary because they always ask whether I have eaten my medicine or not...”* (Participant 3, 47 years old)

## DISCUSSION

Individuals living with congestive heart failure experience changes in their daily lives. Many of these individuals feel profound changes because CHF affected their physical performance, relationships with families and others, and also their purpose in life (Olano-Lizaraga et al., 2020). People suffered from CHF can feel so lonely (Christensen et al., 2019) that they need to possess hope and attain support from people surrounding them (Olano-Lizaraga et al., 2020). Therefore, endeavours to improve the health of people

living with CHF is paramount to be explored in accordance with their daily experiences, feelings and actual needs. This current study contributes new information regarding their feeling after diagnosed, coping mechanism, and need of support especially from families. These findings can be used as information in developing an approach to support such patients to cope with their problems in living their lives.

Having received information in regards to their diagnosis of CHF, patients in this study expressed feelings such as sadness, useless and fear of dying. This is in line with the study by Li, Chang & Shun (2018) that finds several negative emotions in responding to the diagnosis of CHF including fear, helplessness, anxiety and frustration, confirms the study by Hjelm, Andreae & Isaksson (2019) findings which are insecurity, helpless and worrying, and a study by Olano-Lizaraga et al. (2020) that finds CHF sufferer continuously aware of the possibility of dying. One of the reasons for the feelings is because their physical abilities would not be the same as the previous condition (Li, Chang & Shun, 2018). As human being, such feelings can be considered acceptable. Physiological changes experienced by individuals with cardiac problems, including congestive heart failure, always involve abnormal pulse in particular times and causes physical discomfort. This is easily detectable by sufferers that there is something happens in their bodies. If it is confirmed with the bad news informed by health practitioners regarding their illness and the upcoming possibilities because of it, the psychological reaction may be negative.

Despite the negative reaction, this study also finds that individual living with CHF still have a high hope to recover or have something positive to expect to happen in the future. This results are associated with the findings that it is very important if individuals living with heart failure to have hope during their difficult times (Olano-Lizaraga et al., 2020). According to Feldman & Sills (2013), hope may become a crucial component to improve the adherence of individuals with cardiac disease and has been proven correlating with the behaviour improvement of patients who understand the importance of maintaining health related to heart problems. In this current study, the hope expressed by participants indicate that heart failure persons still hope for something important in their lives. These hopes can be used as their self-power to improve their adherence to treatments or therapies related to their disease in order to achieve better outcomes.

After hearing the diagnosis for the first time, such individuals experiences negative feelings but some participants expressed their positive hope. As life continued,



participants experienced self-efficacy that started from their own coping mechanism. According to Algorani & Gupta (2022), coping represents thoughts and behaviours utilized to manage or reduce stress. Coping mechanism was conveyed by participants after learning about the disease. They immediately sought help to the hospital and obediently undergo treatment. This is line with the study conducted by Son, Lee & Kim (2019) that people with CHF considered health information from health practitioners as importantly crucial. They found the information from healthcare facilities are trustworthy, including when they communicate with doctors and allied health practitioners or gaining from any other credible sources from the facilities. As coping can be adaptive or maladaptive, such acts of the present study can be considered adaptive coping, as it helps individuals deal with stressful situations and minimize distress effectively by seeking assistance from health practitioners, ways that were not found in maladaptive coping.

Besides an active action to seek health assistance, participants in this study also expressing that during their sickness, they become more sincere and resigned to their current condition, accepting the faith. These findings are in line with the study results mentioning adjustment as a way of someone diagnosed with CHF to accept the heart failure condition (Hjelm, Andreae & Isaksson, 2019). Another study also found that people with CHF need accept their situation (Olano-Lizaraga et al., 2020). The sincerity and resignation of the participants in this study may be related to the spiritual coping, as some participants commentary are related to their religion. This confirms the study findings that imply something about the disease may drive persons toward higher levels of spiritual well-being (Clark & Hunter, 2018). The study by Li, Chang & Shun (2018) also states that one of ways to live with CHF is by relying on religious thoughts and seeking consolation. Further exploration in this matter will be necessary to investigate to more understand the connection.

A distinctive and unique result was found in this study that all respondents sought alternative nonmedical treatment including looking for shaman's help or consuming herbal medicines. The involvement of shamans in individuals healing efforts have been common in some communities, including in Chile (Kristensen, 2018), Nepal and India (Tallman, 2022), Malaysia (Rahman, Abdullah & Ishak, 2018) and Indonesia (Wula & Mboka, 2021; Asra, Silalahi & Fijridiyanto, 2020). The practice based on believe that

physical world is also connected to metaphysical world and the spiritual beings related to their ancestry, may be considered effective in solving someone's physical problems. Health practitioners should be aware with this phenomenon as empirical evidence of health efficacy associated with the practice of shaman has been scarce and lack of data. This may influence the approach of health practitioners in dealing with such patients. In relation to herbal medicines, Shaito et al. (2020) states that even though herbal medicines contain potent therapeutic agents, the benefits in terms of clinical therapeutic needed to be secured in the first place through rigid clinical research to eliminate the safety and toxicity concerns. Besides that, consumers should be aware that supplements, other than prescribed, may in fact have actual pharmaceuticals or nothing of value but even pose significant toxic potential (Charen & Harbord, 2020). It is clear that all consumable therapeutic agents should pass through clinical trial to prevent humans from intoxication and eventual physical detrimental effects. Therefore, herbal medicines cannot be safely recommended as adjuvant to prescribed medicines in the wider communities.

The present study also highlights the importance of family support for congestive heart failure patients. Participants in this study demonstrate that being supported by family members make them feel motivated, stress-free, and accompanied. The effectiveness of family supports to the well-being of individuals with CHF has also been demonstrated in many studies. Hudiyawati et al. (2021) state that family support has a significant effect on heart failure individuals self-care. Family support also improve CHF individuals' quality of life (Brennan, 2018; Kyriakou et al., 2020). Thus, health care providers should focus an approach towards supports to the heart failure individuals in order to help them adhere to the therapies and also to maintain or improve their quality of life.

## CONCLUSIONS

This research reveal themes of the experience of individuals living with congestive heart failure. Findings include the feeling after diagnosed CHF, coping mechanism, and the importance of family support. These results highlight important issues regarding the feeling of people with heart failure, the importance of having hope during sickness time, accepting condition and feel motivated and also the need of family members to support the beloved one who suffer from CHF. Overall, descriptions of such experiences provide knowledge and awareness of an important area to consider into the approach towards

dealing with such patients. This can help nurses and other health care providers to understand more broadly about patient perspectives and experiences. It can also promote effective patient engagement for a healthy transition process in order to live well with congestive heart failure.

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