An Exploratory Study of Psychological Changes in Families of Heart Failure Patients

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Abstract. The family plays a significant role in the provision of care for those diagnosed with heart failure. The emergence of family psychological difficulties can be attributed to changes in the patient's health and the challenges encountered in fulfilling one's duty. This study elucidates the psychological transformations encountered by families residing with heart failure and examines the coping mechanisms employed. This research employed a descriptive qualitative approach, utilizing face-to-face in-depth interviews to gather data from relatives of heart failure patients. The participants were recruited using a purposive sampling technique, based on preset criteria. The researchers opted for content analysis as the method of data analysis, employing an inductive approach. The findings of our study revealed the presence of four distinct categories, namely: alterations in the health condition of patients, experiences of anxiety during the provision of patient care, the provision of support, and the utilization of positive coping strategies to manage stresses. The family is confronted with physical alterations, gradual reliance, emotional strain, and the potential exacerbation of the patient's illness. The occurrence of this phenomenon elicits psychological alterations, necessitating the implementation of coping mechanisms to effectively address this issue. One such approach is engaging in both physical and spiritual activity. Health practitioners should take into account the importance of providing sufficient assistance and preparedness to families in order to promote their independence in caring for patients with heart failure. In conclusion, this study elucidates the experiences and perceptions of families residing with heart failure. Ensuring the provision of sufficient care by families and healthcare professionals is of utmost importance in attaining optimal health outcomes for individuals diagnosed with heart failure.

Keywords: Heart Failure, Psychological Changes, Family Member.

1. Introduction

Heart failure is a chronic health condition characterized by a gradual decline in cardiac function, leading to significant rates of both mortality and morbidity in both industrialized

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and developing nations [1]. Cardiovascular disease is the leading cause of mortality globally, with projections indicating a staggering estimate of 23.3 million deaths by the year 2030. The available data indicates that a total of 6.2 million adults in the United States, including approximately 2.2% of the population aged 20 years and older, experience heart failure [2]. Chronic functional impairment of the heart results in a notable decline in the patient's quality of life, accompanied by diminished physical function and vigour [3].

There exists a positive correlation between the rising incidence of heart failure and the escalating socio-economic and psychological challenges experienced by the affected individual's family [4]. Patients experiencing disorders necessitate comprehensive treatment and necessitate the active involvement of their family members [5]. This involvement is crucial as it can influence the patient's values, beliefs, attitudes, and behaviour, so mitigating the exacerbation of the disease [6]. In the given scenario, individuals within a familial context encounter many pressures associated with the dynamics of family existence [7]. The stressors encountered by families arise from various factors including the diagnosis of the patient's illness, the consequences of therapy, the patient's diminished capacity to do everyday tasks, alterations in economic and social circumstances, uncertainties surrounding treatment, and the deterioration of the patient's health [8]. The modifications in the patient's lifestyle have an impact on the living habits of family members engaged in caregiving [9].

The readmission of individuals with heart failure elicits psychological reactions within their families, manifesting as anxiety, depression, and stress [10]. These psychological responses have a greater impact on the patients' mental health and overall quality of life compared to their physical well-being [11]. The objective of this study is to investigate the psychological transformations encountered by families of individuals suffering from heart failure as a result of alterations in the state of the heart failure patients.

2. Methods

2.1. Study Design and Participants

The research employed a qualitative descriptive design. Data was acquired through conducting interviews with family members of individuals diagnosed with heart failure. The present piece of writing adheres to the qualitative reporting requirements. The Consolidated Criteria for Reporting Qualitative Research (CCQHR) is a set of guidelines that aims to enhance the quality and transparency of reporting in qualitative research studies [12].

The individuals who took part in the study were family members affected by heart failure, and they were selected using purposive sampling techniques. The absence of medical records posed a challenge in identifying suitable candidates for inclusion in the study. The inclusion criteria for this study consisted of families in whom a patient had a verified diagnosis of heart failure (HF), and immediate family members who had both expertise in

caring for the patient and resided in the same household. Additionally, participants were required to be fluent in the Indonesian language and had provided their approval to participate in the study by signing an informed consent form. Furthermore, it is requested that consent be granted for the purpose of recording the interview.

2.2. Ethical Consideration

The participants were provided with a comprehensive overview of the research's objectives and were explicitly informed about the voluntary nature of their involvement. Additionally, they were assured that their identities would be safeguarded and kept confidential. Ethical issues are carefully considered prior to, during, and subsequent to conducting an interview. These considerations encompass ensuring that participants comprehend their role, addressing any disagreements that may arise among participants, and safeguarding the welfare of the participants [13]. The research protocol has undergone a thorough assessment and has received approval from the Health Research Ethics Committee under the reference number No.DP.04.03/e-KEPK.1/864/2023.

2.3. Data Collection

The research employed face-to-face in-depth interviews in Indonesian, utilizing an interview guide, at a predetermined time and location in October 2023, with a duration of one month. The data was collected in outpatient cardiology clinics of Regional public hospital. The interviews were carried out inside the confines of the waiting area at the heart failure clinic. The interviews were conducted by BK and recorded using a digital voice recorder, with each session lasting between 30 and 60 minutes. The nonverbal replies of the participants were documented in the field notes. Table 1 displays the members of the HF family that were incorporated in the investigation.

The initial step was conducting instrument testing to assess the appropriateness of the interview guide's content. The interview was carried out utilizing open-ended inquiries. Could you please provide a detailed account of your experience in providing care for a family member diagnosed with heart failure? The interviewer posed further inquiries to delve deeper into the experiences of families providing care for patients with heart failure, based on the responses provided by the participants. Could you please describe your emotional response upon learning about the patient's diagnosis? Could you provide an illustrative scenario that elucidates the experience of those living with heart failure (HF)? What is the impact of the patient's disease on your psychological well-being? How did you address the challenge you encountered?

2.4. Data Analysis

The initial phase of the data analysis phase involves the meticulous transcription of the interview's contents, ensuring a verbatim representation, and subsequently cross-referencing it with the audio recording to verify its precision. The analytical method

involved the participation of three research fellows, namely MJF, IRNL, and NWM. The practice of content analysis employs an inductive approach [14] to facilitate the examination of data and enhance comprehension through multiple comprehensive readings of the transcript. The process of setting and managing data is typically performed using manual means. The subsequent step in the analysis procedure involves the extraction of analysis units, which are subsequently compressed, abstracted, and assigned codes. The predefined codes are organized into subcategories and categories by use of a comparative method that takes into account variations and commonalities in meaning. Subsequently, a comprehensive evaluation and deliberation of the preliminary categories and coding was undertaken by all members of the team, culminating in a consensus being achieved.

Table 1. Family characteristics of heart failure

Characteristic	Frequency (n=20)	Percentage (%)
Gender		
Male	5	25
Female	15	75
Age		
25-35	2	10
36-45	4	20
46-55	7	35
56-65	5	25
66-75	2	10
Job		
Midwife	1	5
Labor	2	10
Teacher	1	5
Housewife	7	35
Farmer	5	25
Civil servants	1	5
Entrepreneur	3	15
Last Education		
Bachelor	4	20
Diploma	1	5
High School	5	25
Middle School	3	15
Elementary	5	25
Uneducated	2	10
Relationship with Patients		
Child	8	40
Mother	1	5
Couple	10	50
Relation	1	5

Characteristic	Frequency (n=20)	Percentage (%)
Duration of Care		
<1 year	12	60
1-2 year	2	10
>2 year	6	30

2.5. Rigour

The enhancement of trustworthiness is crucial in order to promote both completeness and trust in the findings of research [15]. The maintenance of research credibility is upheld through the implementation of an interview procedure conducted by individuals possessing expertise in qualitative research. Furthermore, the outcomes of trial interviews are deliberated upon with colleagues who possess specialized knowledge in the field of qualitative research. Furthermore, the research team engaged in discussions regarding the findings. Enhancing transferability can be achieved through the provision of a comprehensive depiction of the research setting, participant attributes, interview procedures, data processing, and presentation of conclusions accompanied by direct quotations. The involvement of three people from the study team in data processing and subsequent discussions over final categories resulted in an enhanced level of dependability. The confirmability of research findings is enhanced through the corroboration of information provided by participants.

3. Findings

3.1. Changes in the Patient's Health Status

Changes in health status in heart failure sufferers, such as declining health, recurrence and readmission are factors that trigger family anxiety. The following are participant statements regarding changes in health conditions and relapses experienced by HF patients.

"Relapse...symptoms of shortness of breath...chest pain, so I had to be hospitalized again" (participant 6).

3.2. Anxious while Caring for Patients

The anxiety felt by the family is one of the psychological changes during caring for HF patients. The anxiety felt by the family is caused by feelings of worry, shock, sadness about the patient's condition. The following are participant statements showing anxiety symptoms while caring for HF patients:

"Fearful if a sudden cardiac arrest occurs" (participant 19).

3.3. Give Support

Positive responses such as providing psychological support to HF sufferers during the treatment process. Feelings of caring are the reason families choose to provide support to

HF sufferers. Family support is the family's attitudes, actions and acceptance of the sufferer's condition. Examples of support quotes provided by families are as follows.

"Comforting the patient and providing encouragement so that the patient will continue to try to recover" (participant 4)

3.4. Positive Coping Mechanisms for Dealing with Stressors

While caring for HF patients, families are faced with various stressors, such as physical changes in the patient, economic limitations, and various obstacles faced during the treatment process. The various changes that occur are factors that trigger family psychological changes. To deal with stressors, participants chose to engage in spiritual activities as a coping mechanism. Excerpts from participants' expressions that show spiritual activity as a coping mechanism are as follows.

"Surrender yourself to Allah, pray and pray for peace and health so you can care for patients" (participant 20)

The study highlighted four primary categories: alterations in the patient's health condition, apprehension experienced during patient care, provision of support to the patient's family, and utilization of constructive coping strategies to manage stressors. Families affected by heart failure encounter difficulties when fulfilling their responsibilities in providing care for patients within the home setting. Healthcare providers may experience feelings of worry or apprehension when faced with a decline in a patient's health state that necessitates readmission. The family endeavours to comprehend and address the situation through the provision of emotional support. One of the tactics employed by families in response to psychological changes resulting from the patient's condition and the difficulties encountered in providing care include seeking solace in their faith, particularly by deepening their connection with Allah. Table 2 presents a compilation of research outcomes, along by their respective code and meaning units.

Table 2. Example Outcomes of content analysis

Example of meaning unit	Example of Codes	Subcategories	Categories
Body weak, shortness of breath, chest pain	Symptoms of recurrence	Causes of family psychological changes	Causes of family psychological changes
Fear of bad things happening	Anxious	Emotional response	Anxiety during treating patients
Encouraging	Emotional support	Positive response	Providing support
Pray	Worship God	Physical and spiritual activity	Positive coping mechanisms facing stressors

4. Discussion

This research elucidates the transformations encountered by families that are responsible for the care of a family member diagnosed with heart failure (HF). The primary outcomes delineate the catalysts for alterations in familial psychological states. Based on our research findings, a range of physical ailments such as dyspnea, angina, and weariness were observed to induce emotional distress, including worry and fear. These observations align with prior investigations undertaken in this field [16]. Additionally, the care of individuals with heart failure was found to result in changes in daily living, as well as exhaustion and anxiety among family members [17]. Consistent with prior research, our findings indicate that the observed alterations in the circumstances of patients with heart failure led to emotional distress among their family members [18].

The families of individuals diagnosed with heart failure experience a gradual and unavoidable reliance on others as a result of the patient's declining physical well-being. The study revealed that families experienced heightened levels of anxiety as a result of their concerns around the potential loss of their loved ones. Families employ various measures in order to mitigate the effects of psychological alterations that are encountered. According to participants in our research, familial individuals acknowledged experiencing psychological shifts as a result of the patient's health condition. Nonetheless, they recognized the importance of attending to the patient's psychological well-being, so ensuring the continuation of their supportive role. According to a study, relatives of individuals with heart failure (HF) employed two primary coping mechanisms, namely physical and spiritual dimensions [19]. The act of sharing experiences among family members who have been affected by heart failure serves to enhance and fortify familial bonds. The findings of a study conducted on patients diagnosed with heart failure revealed that spirituality emerged as a prominent coping mechanism employed to navigate the challenges associated with fluctuating health conditions [20].

There are various limitations inherent in the conclusions of this study. The majority of the individuals within the family were female partners (n=15), who had a longer duration of caregiving ranging from 1 to 12 months (n=12). Hence, the implications of our study can be broadened for future research by incorporating the perspectives of partners of men with HF and extending the duration of patient treatment, so enhancing our understanding of the psychological transformations experienced by families living with HF.

5. Conclusion

The study's results indicated that families of individuals with heart failure underwent psychological transformations during the process of caregiving. The deterioration of the patient's health status and the apprehension of adverse outcomes elicit alterations in family psychology. In addition to this, it is imperative for the family to possess the capacity to offer assistance to the patient in light of the observed decline in their condition. The utilization

of spiritual coping techniques represents the deliberate decision made by the family to address the psychological transformations experienced by its members. Health practitioners must take into account the crucial factors of providing sufficient support and promoting family independence when preparing families to assume the role of patient companions for individuals with heart failure (HF). The comprehension of family narratives and their requirements in the provision of care for patients with heart failure (HF) is crucial in attaining the highest level of HF care.

Authors' Contributions

The interviews were conducted by BK, who also handled data management, performed data analysis, and prepared the initial manuscript. All authors contributed to the conceptualization of the research, the design of the study, the analysis of the data, and the interpretation of the findings. Furthermore, engage in a thorough evaluation of the publication manuscript, employing a critical lens, and ultimately grant final endorsement to the selected iteration for dissemination.

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References

1. M. Arrigo *et al.*, "Acute heart failure," *Nat. Rev. Dis. Prim.*, vol. 6, no. 1, p. 16, 2020, doi: 10.1038/s41572-020-0151-7.
2. E. J. Benjamin *et al.*, *Heart Disease and Stroke Statistics-2019 Update: A Report From the American Heart Association*, vol. 139, no. 10. 2019. doi: 10.1161/CIR.0000000000000659.
3. I. Johansson *et al.*, "Health-Related Quality of Life and Mortality in Heart Failure: The Global Congestive Heart Failure Study of 23 000 Patients From 40 Countries," *Circulation*, vol. 143, no. 22, pp. 2129–2142, Jun. 2021, doi: 10.1161/CIRCULATIONAHA.120.050850.
4. Kubzansky L *et al.*, "Positive Psychological Well-Being and Cardiovascular Disease: JACC Health Promotion Series. J Am Coll Cardiol [revista en Internet] 2018 [acceso 10 de octubre de 2022]; 72(12): 1382-1396.," vol. 72, no. 12, pp. 1382–1396, 2019, doi: 10.1016/j.jacc.2018.07.042.Positive.
5. R. Dehbozorgi, M. Fereidooni-Moghadam, M. Shahriari, and E. Moghimi-Sarani, "Barriers to family involvement in the care of patients with chronic mental illnesses:

A qualitative study ," *Frontiers in Psychiatry* , vol. 13. 2022. [Online]. Available: https://www.frontiersin.org/articles/10.3389/fpsyt.2022.995863
6. B. Riegel, V. V. Dickson, and E. Vellone, "The Situation-Specific Theory of Heart Failure Self-care: An Update on the Problem, Person, and Environmental Factors Influencing Heart Failure Self-care," *J. Cardiovasc. Nurs.*, vol. 37, no. 6, 2022, [Online]. Available: https://journals.lww.com/jcnjournal/fulltext/2022/11000/the_situation_specific_theory_of_heart_failure.3.aspx
7. L. R. Bangerter, J. M. Griffin, and S. M. Dunlay, "Positive Experiences and Self-Gain among Family Caregivers of Persons with Heart Failure," *Gerontologist*, vol. 59, no. 5, pp. e433–e440, 2019, doi: 10.1093/geront/gny162.
8. D. Randazzo and K. B. Peters, "Psychosocial distress and its effects on the health-related quality of life of primary brain tumor patients," *CNS Oncol.*, vol. 5, no. 4, pp. 241–249, 2016, doi: 10.2217/cns-2016-0010.
9. R. Phillips, M. Durkin, H. Engward, G. Cable, and M. Iancu, "The impact of caring for family members with mental illnesses on the caregiver: a scoping review," *Health Promot. Int.*, vol. 38, no. 3, p. daac049, Jun. 2023, doi: 10.1093/heapro/daac049.
10. Y. A. Sumaqa *et al.*, "Consequences of Psychological Aspects: From Jordanian Heart Failure Patients' Beliefs," *SAGE Open Nurs.*, vol. 9, p. 23779608231189130, Jan. 2023, doi: 10.1177/23779608231189128.
11. K. Ruggeri, E. Garcia-Garzon, Á. Maguire, S. Matz, and F. A. Huppert, "Well-being is more than happiness and life satisfaction: a multidimensional analysis of 21 countries," *Health Qual. Life Outcomes*, vol. 18, no. 1, p. 192, 2020, doi: 10.1186/s12955-020-01423-y.
12. A. Tong, P. Sainsbury, and J. Craig, "Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups," *Int. J. Qual. Heal. Care*, vol. 19, no. 6, pp. 349–357, 2007, doi: 10.1093/intqhc/mzm042.
13. B. Voltelen, H. Konradsen, and B. Østergaard, "Ethical considerations when conducting joint interviews with close relatives or family: an integrative review," *Scand. J. Caring Sci.*, vol. 32, no. 2, pp. 515–526, 2018, doi: 10.1111/scs.12535.
14. U. H. Graneheim, B. M. Lindgren, and B. Lundman, "Methodological challenges in qualitative content analysis: A discussion paper," *Nurse Educ. Today*, vol. 56, no. May, pp. 29–34, 2017, doi: 10.1016/j.nedt.2017.06.002.
15. S. Elo, M. Kääriäinen, O. Kanste, T. Pölkki, K. Utriainen, and H. Kyngäs, "Qualitative Content Analysis," *SAGE Open*, vol. 4, no. 1, p. 215824401452263, 2014, doi: 10.1177/2158244014522633.
16. M. Moshki, A. Khajavi, H. Hashemizadeh, F. Vakilian, S. Minaee, and S. S. Martin, "Dark or bright half of the moon: A qualitative study exploring the experience of Iranian heart failure patients regarding their quality of life," *Open Access Maced. J. Med. Sci.*, vol. 7, no. 5, pp. 824–830, 2019, doi: 10.3889/oamjms.2019.189.
17. R. C. Austin, L. Schoonhoven, M. Clancy, A. Richardson, P. R. Kalra, and C. R. May, "Do chronic heart failure symptoms interact with burden of treatment?

Qualitative literature systematic review," *BMJ Open*, vol. 11, no. 7, 2021, doi: 10.1136/bmjopen-2020-047060.

18. M. Shamali, B. Østergaard, and H. Konradsen, "Living with heart failure: Perspectives of ethnic minority families," *Open Hear.*, vol. 7, no. 1, pp. 1–8, 2020, doi: 10.1136/openhrt-2020-001289.
19. Y. P. Lin, C. H. Fan, K. Z. Tsai, K. H. Lin, C. L. Han, and G. M. Lin, "Psychological stress and long-term blood pressure variability of military young males: The cardiorespiratory fitness and hospitalization events in armed forces study," *World J. Cardiol.*, vol. 12, no. 12, pp. 626–633, 2020, doi: 10.4330/WJC.V12.I12.626.
20. M. A. Liljeroos, J. L. Miller, T. A. Lennie, and M. L. Chung, "Quality of life and family function are poorest when both patients with heart failure and their caregivers are depressed," *Eur. J. Cardiovasc. Nurs.*, vol. 21, no. 3, pp. 220–226, 2022, doi: 10.1093/eurjcn/zvab071.

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