



Lived Bodily Experience of Worsening Heart Failure from Acute Exacerbation to Recovery: A Phenomenological Study

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博士論文

Lived Bodily Experience of Worsening Heart Failure from Acute Exacerbation to Recovery: A Phenomenological Study

（急性増悪から回復までの心不全悪化の生きられた身体的経験：現象学的研究）

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Abstract

Patients with heart failure have difficulty recognizing and identifying changes in bodily sensations, despite the importance of symptom monitoring. The way patients with heart failure experience their bodies from exacerbation to recovery is poorly understood. We aimed to describe the lived bodily experience of heart failure from exacerbation to recovery. Participatory observations and interviews were conducted in seven patients admitted to the intensive care unit with worsening heart failure. Benner's interpretive phenomenology was used for analysis. Four major themes were identified: a non-functional body becomes the central concern and an object; being conscious of bodily changes before hospitalization when asked; the central concern shifted to daily life and the body becomes the background; and having a feeling of death in the body that no longer functions or a weakened body after recovery. This study found that patients with heart failure were conscious and concerned about their bodies changing as they underwent rapid changes during exacerbations and recovery. In addition, immediately after their bodies recovered and until they were discharged from the hospital, they looked toward their daily lives through their bodily experiences during heart failure exacerbation. The lived bodily experience of heart failure, which is less conscious in daily life, is made conscious through storytelling in the period immediately following recovery from an acute exacerbation and can be the

basis for subsequent self-care exploration.

Introduction

The recognition of symptoms is crucial for the successful self-management of heart failure (HF) (1–3). Patients who could monitor their HF symptoms have been reported to better adhere to treatment (4). Delays in treatment initiation due to delayed recognition and response to HF symptoms result in increased mortality and rehospitalization rates (5, 6). Therefore, early recognition and appropriate response to symptoms of worsening HF are essential for effective management. However, patients with HF have reported difficulty in recognizing their symptoms and might delay seeking medical assistance (7, 8). Despite the availability of intervention studies targeting symptom recognition, there is no consensus regarding their efficacy (9). Therefore, it is a challenge for medical professionals to support patients' perception of HF symptoms and manage them appropriately.

Enhancing body awareness is critical for patients to detect symptoms of HF exacerbation at an early stage. HF symptom perception involves the identification, recognition, and interpretation of bodily sensations (3). Some studies have reported that patients with HF primarily relied on their physical experience of “how it feels” in their bodies rather than on clinical symptoms of HF exacerbation (10). In other words, the subjective experience of HF symptoms in the body is crucial for patients to perceive the symptoms of HF exacerbations. Sensitivity to bodily sensations has also been associated with body awareness (7). Therefore, it is essential to increase body awareness to detect changes in bodily sensations that may be indicative of HF exacerbation.

Maintaining awareness of one's body while engaging in daily life is often challenging. People often

live without a clear understanding of their bodies (11). Individuals with chronic illnesses may have symptoms so ingrained in their lives that they struggle to recognize them separately (12). Patients with HF often struggle to detect symptoms of exacerbations at an early stage (13–15); they can also have difficulty examining their bodies (16–17) and can, therefore, be unsure about the physical changes associated with HF exacerbations (18). To help patients with HF become more interested and aware of changes in their bodies, it is crucial that healthcare providers better understand the lived bodily experiences of patients with HF and provide support that is consistent with those experiences.

The experience of the body of a patient with HF may be inferred from their recovery from acute exacerbation to when the symptoms change rapidly. While patients with HF generally tend to overlook chronic symptoms, such as weight gain, edema, and other daily-life experiences (19), they are more aware of severe symptoms, such as shortness of breath, which may prompt a visit to the emergency room (20). Many patients with HF can describe their experiences of worsening HF following the resolution of an acute exacerbation. This provides two significant insights—first, that patients’ bodily experiences may change as their symptoms change, and second, that they may be able to recall gradual changes in their body and mental status, including their experiences prior to emergency hospitalization and during the period immediately following recovery. Therefore, gaining a deeper understanding of the experience of acute HF exacerbation from its onset to recovery could provide valuable insights into the live bodily experiences associated with patient symptoms.

To this point, inadequate consideration has been given to the lived bodily experiences of individuals

during the exacerbation and recuperation phases of HF, particularly those that are not explicitly recognized. Prior research has predominantly concentrated on how patients perceive symptoms, particularly those that they did and did not perceive (21–23), the obstacles and consequences of physical observation and analysis (19, 24, 25), and how they coped with symptoms (26–28). However, this emphasis on perceived experiences has not uncovered the unperceived experiences of patients (i.e., experiences in which patients are not explicitly cognizant). Patients with HF often experience gradual symptom intensification without conscious awareness. As the illness progresses, they become more cognizant of their symptoms. Hence, it is crucial to understand lived bodily experiences, including symptoms that patients may not perceive clearly.

The purpose of this study was to describe the lived bodily experiences of patients with HF from exacerbation to recovery and to offer recommendations for improving symptom perception in such patients.

MATERIALS AND METHODS

Design

This study used the interpretive phenomenological methodology developed by Benner (29). The objectives of interpretive phenomenological research are to explore the lived experiences of particular phenomena and to derive existence from forgetting (30). As the bodily experiences of patients with HF are vague and patients often struggle to explain them clearly, this methodology was considered

suitable for understanding the bodily experiences with worsening HF (29, 31). However, as it is difficult to perform these actions during severe acute exacerbation of HF, we initiated participatory observations and interviews after the patients had recovered from the acute stage to some extent and were able to talk.

Participants

This study was conducted in the cardiac care unit (CCU) and cardiology ward of an acute care hospital in Japan. The objective of this study was to explore the lived bodily experience of patients with HF from acute exacerbation to recovery. Therefore, a purposive sampling method was employed to select patients who had a previous diagnosis of HF and required hospitalization because of acute exacerbation (32, 33). The sample size was considered adequate when interpretations were understandable and clear and new informants revealed no findings and meanings different from all previous narratives (29, 31). Patients were selected according to the following criteria: age >20 years; HF diagnosed more than 6 months ago; emergency hospitalization for worsening HF; stable circulatory dynamics and capable of talking for approximately 30 min; no serious communication problems; and listened to the researchers' explanation and signed the consent form.

The CCU nursing managers and cardiovascular specialists selected the patients based on these criteria and referred them to the principal investigator. A female nurse who did not work in the study ward was the interviewer and observer (lead author). The interviewer (lead author) explained the

content of the study to patients who were interested in participating using a study manual, answered the patients' questions, provided them with the consent forms, and began participatory observation after the patients had signed the consent forms. None of the patients who were briefed by the interviewer (lead author) declined to participate. However, one female patient who signed the consent form voluntarily withdrew consent after the participatory observation. Another male patient withdrew his consent because his condition worsened after signing the consent form.

Data collection

Data were collected between January and June 2015. Before the interview, the patients' sociodemographic data were collected (Table I). After patient registration, we conducted participatory observation (by the lead author) in the CCU with the participants' consent. Participatory observations were conducted while the participants were admitted to the CCU and took place in a daily living support setting and during examination and treatment. A participant observer (lead author) observed each scene with the participant's consent. Brief notes were taken during participant observation, and immediately after the observation was completed, the scene and the patient were transcribed in writing and used for analysis. Interviews were conducted by the lead author. The first interview was conducted within 0–2 days after each patient was transferred to the cardiovascular ward, and the second interview was conducted between 5 and 40 days after admission when discharge was being considered. A third interview was conducted on another day if the interview was interrupted owing to patient physical

considerations or examination. Each interview lasted approximately 30 min and was recorded. Two to three interviews were conducted with each participant. Each interview began with questions such as “What kind of bodily changes from before hospitalization to the present day did you notice?” The researcher asked participants to freely share bodily details observed during worsening HF. Interviews were recorded using a voice recorder (Sony IC recorder, ICD-UX543F/UX544F; Sony Corp., Tokyo, Japan) for transcription. Field notes (e.g., voice tones, gestures) and body position observations were also included to enhance the interpretation of the recording.

Ethical considerations

This study was approved (approval number: 313) by the Ethics Committee of Kobe University Graduate School of Health Sciences and was conducted in accordance with the Declaration of Helsinki (as revised in 2013). The participants were allowed to decide whether to participate in the research and could opt out at any time. We explained that the nursing care or treatment would not be affected by not participating in the study, research cooperation could be suspended at any time, and personal information would be protected. Consent was obtained from the participants prior to their inclusion in the study; participants were also informed that their anonymity would be preserved.

Data analysis

The interpretive phenomenological methodology by Benner (29) was used for data analysis.

Thematic analyses were mainly conducted by the lead and second authors. Participatory observation field notes and interview audio data were transcribed verbatim (31). First, the verbatim paradigm case records were read, and the overall meaning of the participants' experiences was understood. The content relating to the phenomenon to be studied was extracted from the verbatim paradigm case records. Topics repeated or raised by the participants and contradictory narratives were extracted, and the meanings that emerged from key sentences were systematically described.

An overall interpretation of the paradigm case was described. The same procedure was used to interpret the second and subsequent cases. All cases and situations were analyzed to identify and describe the commonalities and differences in patient experiences. The formulated materials were organized into several themes. The original data were referred to several times to ensure that each theme was accurate. Participants did not provide feedback on the findings. However, at the subsequent interview, we verified the information from the previous interview.

Several observations and interviews were conducted to ensure the reliability of the data, wherein topics from previous interviews were pursued from various angles, and a follow-up was conducted (30). There were also repeated discussions on the transcripts and themes within the research team, and under the supervision of a qualitative researcher (fifth author) and a phenomenologist (third author), we conducted a detailed discussion and refinement of the findings.

RESULTS

The participants in this study included two men and five women aged 62–88 (mean: 76) years. All participants were admitted to the CCU as an emergency, owing to worsening HF. The average length of stay at the CCU was 2–4 (mean: 2.7) days, and all patients were classified as New York Heart Association class IV (Table I). The participant observations and interview analyses revealed that patients with HF were conscious of their bodily changes during worsening HF. They were thinking about everyday life and life after discharge through such bodily experiences. The following four major themes were identified from the participatory observation and interview analyses.

Table I. Outline of the research participants (n = 7)

	A	B	C	D	E	F	G
Age (years)	77	87	88	80	74	62	64
Sex	Male	Female	Female	Female	Female	Female	Male
Prior hospitalization history for heart failure	1	0	0	0	0	1	1
NYHA class at the time of hospitalization	IV	IV	IV	IV	IV	IV	IV
Length of stay in the CCU	2 days	2 days	2 days	3 days (1 st) 6 days (2 nd)	2 days	4 days	4 days
Length of hospital stay	16 days	15 days	25 days	65 days	25 days	35 days	15 days
Re-entry to CCU	No	No	No	Yes	No	No	No
LVEF at the time of hospitalization	60%	50%	46%	30%	40%	47%	44%
Medical history excluding heart failure	HTN CKD	CAD HTN	HTN DM	HTN CKD CI	HTN CKD CI	DCM AF HTN CKD CI DM	DCM SSS IP DM dysthyroidism

AF, atrial fibrillation; CAD, coronary artery disease; CCU, cardiac care unit; CI, cerebral infarction; CKD, chronic kidney disease; DCM, dilated cardiomyopathy; DM, diabetes mellitus; HTN, hypertension; IP, interstitial pneumonia; LVEF, left ventricular ejection fraction; n, sample size; NYHA, New York Heart Association; SSS, sick sinus syndrome

Theme 1. A non-functional body becomes the central concern and an object

A central concern of all participants was the sensations they experienced in their bodies before and after their emergency hospitalization, feeling that their bodies were losing their ability to maintain life. These sensations were described in detail during participatory observation in the CCU and in interviews immediately after leaving the CCU. For instance, they reported the following experiences: “unable to breathe,” “severe heart palpitations,” “unable to digest food,” and “unable to sleep.” Their narratives about the physical conditions of the time were detailed and sometimes objective. Some individuals provided detailed and precise descriptions of the situation.

Mr. A provided a detailed account of his breathing when the ambulance arrived, as well as his premonition of death without exhibiting any impatience or agitation.

“The ambulance came here. I was sitting and sleeping the whole time. I would just keep breathing in. Breathing in, then out, in, and then out. Kept breathing in. When I was breathing in, I could breathe in when I tried, but when I breathed out, it would just come out in bursts, like, ‘hah,’ ‘hah,’ ‘hah,’ ‘hah’ [omitted]. I was just thinking, am I going to die?” (Mr. A)

Ms. D recounted in detail the progressive diminishment of her capacity to eat in the days preceding her urgent hospitalization.

“I couldn’t eat even one meal a day anymore, and even if I wanted to eat ramen, I couldn’t eat even

one meal. I thought I'd eat some porridge (while making small circles with her hands) in the morning.

I thought it would be better to eat spinach, but I couldn't eat it at all. Milk and things like that were fine, but I couldn't eat rice or other foods like that. Even if I felt like I should eat something, all I could eat was sakuramochi (steamed bun with a sweet bean paste filling) and tea.” (Ms. D)

The narratives concerning the period just before emergency hospitalization, wherein participants experienced pain so severe that they thought they would die, were somewhat objective and often spoken of as if they were about another person. Additionally, although the circumstances were urgent, patients would speak in what could be interpreted as an easy-going tone, with phrases, such as “Ah, this was bad,” or “I was just thinking what an ordeal.”

Ms. B described the sound of her breathing when she was having difficulty breathing as if “something” other than herself was making the sound.

“I was very, very still, but after a while, a ‘hee, hee, hee, hee,’ that came out was almost like a flute. Every time I breathed, a ‘hee, hee, hee, hee’ [imitating sound], something like that, and I was just so surprised.” (Ms. B)

Ms. C was hospitalized due to severe palpitations that prevented her from sleeping. When asked about the reason for the emergency hospitalization, she said “The Dr. told me to come to the hospital.”

"I had heart palpitations so bad I couldn't sleep at night. My lungs were pounding. I thought, 'Ah, this was bad, I wonder why,' so I called Dr., and he came to see me. Well, I came here because he said, 'I can't handle it, so you'll have to go into the hospital.'" (Ms. C)

Theme 2. Being conscious of bodily changes before hospitalization when asked

After sharing their bodily experience of emergency hospitalization, when asked, participants also mentioned vague bodily discomfort unrelated to their known HF symptoms that occurred several months to weeks before their emergency hospitalization. This vague bodily discomfort included factors such as urine properties and volume, foot edema, and blood pressure, in addition to a subtle malaise that would not be noticed unless paid attention to daily. Participants described such discomfort using expressions such as "something strange happened" instead of reporting HF symptoms.

During our conversation, Ms. D indicated that she was not experiencing any symptoms. However, upon further reflection, she remembered how exhausted she was.

"Well, I woke up to go to the toilet and urinated, but I didn't really notice any symptoms. Since I was sleeping, I didn't get enough exercise, so I thought I was exhausted. I was surely exhausted. I was a little exhausted." (Ms. D)

Ms. F. said that she was not exhausted. However, as she continued speaking, she recalled that she

had some discomfort in her throat.

“I was not exhausted. I thought my throat was slightly swollen. By the time the evening came around, I felt a little hot. Maybe my throat felt sore. It didn’t hurt, but it felt like it’s a strange feeling.” (Ms. F)

Mr. G reportedly experienced a hoarse voice and a little difficulty speaking prior to the onset of his breathing difficulties.

“I can breathe normally. But, I’m feeling like my voice has become hoarse and it’s bothering me. [omitted] This was not originally the case. When I’m not feeling well, I feel something like this. It’s like it’s hard for me to talk about it myself.” (Mr. G)

Some participants gradually remembered the bodily changes they experienced before emergency hospitalization during the interview. The participants did not think that their vague bodily discomfort was a symptom of HF. The participants reported that they were trying to understand the meaning of their vague bodily discomfort in the context of their experience and from what they heard from others. Examples included kidney disease, lack of exercise, and food consumption.

During Ms. B’s reflection on the physical changes preceding her hospitalization, she remembered that several months prior, her urine had exhibited peculiar characteristics. She then tried to understand

her own experience.

“Last year, I think it was around springtime, my urine volume decreased. [omitted] There was foam in my urine, sort of just bubbling foam, you see, and I was thinking, how strange. Is it supposed to be foamy? I have never really heard about that, and I have never really seen that.” (Ms. B)

Ms. C was aware of the feeling that things were difficult but vaguely thought it was due to a lack of exercise.

“I was able to go to the bathroom, and I could pee, so [there were no] subjective symptoms. I was sleeping, so the most I thought of it was that things were difficult because of a lack of exercise.” (Ms. C)

Theme 3. The central concern shifted to daily life and the body becomes the background

In interviews, when discharge became a reality, most participants' narratives were about daily life and less about the body as an organ, with decreased focus on symptoms, signs, and physical sensations. All participants could walk, use the toilet, have a shower, and do other daily activities, and felt that they were recovering physically. However, they also realized that it was not enough to return to life after discharge, and their focus was mainly on whether they could carry out their daily life with their

body at that time.

Ms. D, who could hardly eat anything prior to her hospitalization felt recovered at mealtime.

"Sometimes I find the food I'm served (hospital food) delicious, and sometimes I find it's lacking.

Well, whatever I eat is delicious. When I feel that way, I think, oh, I've recovered. I shouldn't say that,

but hospital food can't possibly be that delicious, but it tastes delicious." (Ms. D)

As Ms. B was able to walk, she began to worry about whether she would be able to make it to the supermarket.

"I can walk, but I can't go to the supermarket. That's why I said, 'Doctor, I'm fine, but I can't go

to the supermarket. I have to be able to walk to the supermarket.' Then the Doctor said 'It's okay, Ms.

B.' So, from tomorrow or today, I will rehabilitate on the 3rd floor (rehabilitation) or something (go)."

(Ms. B)

When Ms. E was able to walk freely around the ward, she wanted to be able to walk and run longer distances. However, she was worried about sudden movements.

"I'll do it to the best of my ability. Don't say more than that. It's not good to run all at once. If you

keep increasing the number of kilometers, it will happen again. It's the same thing. I think I'll be

careful.” (Ms. E)

Theme 4. Having a feeling of death in the body that no longer functioned or a weakened body after recovery

Most participants said they “thought they were going to die” regarding the symptoms that they experienced immediately before and after emergency hospitalization. Furthermore, many spoke with an awareness of death even after their symptoms were alleviated, and they had begun to think about daily life after being discharged from the hospital.

Ms. E. said of her disease: *“The heart is scary.”*

“The heart is scary. It is all over if it goes bad, even just a little bit.” (Ms. E)

Mr. A, who mentioned how his systolic blood pressure had risen to 220 mmHg immediately before hospitalization, said that his experience was similar to that of a family member who died of hypertension.

“It’s scary. My parents had high blood pressure after all. Yes, that’s why I thought the cause was genetic. My parents died from blood pressure, and my older brother died from blood pressure. Actually, my sister also had blood pressure and collapsed at the entrance.” (Mr. A)

During the second interview, many participants expressed the remaining time they had left in their lives as a fixed period of 5 or 10 years. Some participants mentioned that they could live for another 10 years as they could move their body parts. Other participants could not move as they wished and experienced physical deterioration, resulting in an expectation that they would have a shortened life.

Ms. F felt the sensation of not being able to turn over as she wished, felt that she would never be able to return to her original body, and described the rest of her life as 5 to 10 years.

“This means that I am unable to return to my former body. Being able to roll over with my own strength [omitted]. I would like to be able to do my own things by myself. I am not quite at the age where I can rely on my children in terms of age. I do not know if this would be the case if I was 72 (years old) or something else. I think I would like to live for at least 5 to 10 years.” (Ms. F)

Mr. G thought he would never have HF again, but he realized that was not the case. He also described his heart as a battered engine and thought the only way to keep it running was to trick it with drugs.

“I thought that if I just watched the progress, I wouldn’t suffer from HF or anything like that. That’s not the case. [Omitted] I don’t know what to say, but basically, it’s not getting better. I’m suffering from HF and my pulse is fast, but I think it’s basically dilated cardiomyopathy, which means that the engine is no longer functioning properly. So, it’s like, I can trick it with drugs or something and see

how many kilometers I can run.” (Mr. G)

DISCUSSION

This study found that patients with HF were conscious and concerned about their bodies changing as they underwent rapid changes during exacerbations and recovery. In addition, immediately after their bodies recovered and until they were discharged from the hospital, they looked toward their daily lives through their bodily experiences during HF exacerbation.

When everyday life was disrupted because of severe symptoms and the body began to lose functions, the central concern of participants shifted to the body, and they were clearly conscious of their body and objectified it. Benner and Wrubel stated that in the presence of a symptom, even as the person’s attention becomes focused on the bodily sensation of the symptom, he or she begins to interpret it and form his or her own diagnosis (34). Prior research has reported that severe HF symptoms were easily recognized (10, 35, 36), and HF was reported to be the cause (37, 38). This may be because the loss of bodily functions due to deterioration of HF shifted the central concern of the body and facilitated the objectification of the body and the interpretation of changes in it.

A characteristic of the narratives of bodily experiences in everyday life was that patients vaguely remembered them but could explain them when asked. Patients with HF had difficulty recognizing early symptoms of HF (17, 39) and were able to identify or name the feeling that something was wrong before the initiation of symptoms (23, 40). However, the reason for this is unclear. This study’s results

suggest that, as proposed by Merleau-Ponty, in daily life, patients cope with illnesses and symptoms through their habitual bodies (41). In this way, the body is submerged in the background of everyday life, so it may be extremely difficult to objectively perceive, interpret, and give meaning to the symptoms in everyday life.

Once the participants were able to live their daily lives and began to think about discharge, the focus of their concerns shifted to their daily lives, but their bodies were always in the background. In other words, they were thinking about their daily lives after discharge and their death through their bodies. Previous studies reported that patients with chronic HF reevaluated the meaning of their lives, developed a new perspective on chronic HF, and discovered deeper meaning through their hospitalization experience (42). Our study findings revealed that patients' HF perceptions of post-discharge daily lives and death were conducted through their bodily experiences. In other words, bodily experience is considered a central experience in reinterpreting post-discharge daily life and death.

Experiencing lived bodily experiences alone is insufficient for effective symptom perception. In this study, participants thought about their daily lives after discharge through their bodies but did not directly link these experiences to HF. Previous research has also indicated that hospitalization for acute exacerbation is insufficient to improve symptom perception. Patients who were hospitalized for HF delayed seeking treatment (7). Moreover, a literature review on symptom perception revealed that the relationship between HF hospitalization experience and symptom perception was inconsistent (43). In

other words, mere experience is not sufficient to relate symptom experience with appropriate symptom perception. However, if healthcare professionals could educate patients with HF about HF experience, they may realize and make sense of it as the beginning of worsening HF when they experience similar symptoms after discharge from the hospital.

The study findings have two significant implications for nursing support. First, during the immediate post-recovery period from an acute exacerbation of HF, healthcare providers should inquire about patients' bodily experiences with HF and connect these experiences to their bodies. The study revealed that patients with HF discussed their bodies during this period when asked and that they became more aware of changes in their bodies upon prompting. Therefore, by asking about bodily experiences and attributing them to worsening HF, healthcare providers can help patients interpret the changes in their bodies as symptoms of HF. Additionally, as discharge becomes a more tangible prospect, patients may benefit from discussing how they can notice changes in their bodies during their daily lives. This may increase their awareness of less noticeable changes in their bodies and improve their ability to perceive symptoms in daily life after discharge. Therefore, healthcare providers should consider focusing on and questioning patients' bodily experiences and link these experiences to HF when their interest in their body and daily life is changing.

Limitations

A limitation of this study is that participants recalled their acute exacerbation experiences after

recovery. We believe that the patient's experience from acute exacerbation to the interview may influence their narrative of the experience. Additionally, the participants in this study were individuals who presented with severe symptoms, necessitating admission to the CCU. The lived bodily experiences of patients with HF who have never been hospitalized for HF or have limited experience with subjective HF symptoms may vary. Therefore, future studies should consider including patients with HF who have never been hospitalized or who did not experience subjective symptoms at the time of hospitalization for HF.

Conclusions

This study described the bodily experiences of patients during emergency hospitalization owing to worsening HF. When the body became non-functional due to worsening HF, patients began to objectify their body and, through their descriptions, captured it clearly and in detail. Patients with HF could remember and talk about bodily changes of which they had not been clearly conscious before admission when asked. Even after their central concern shifted to their daily life, their body was still salient in the background of their consciousness, and they were always looking through the lens of their body at their everyday life and life after discharge.

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