**Supplementary Material**

# How do Japanese patients with chronic heart failure view their disease, self-care, and support?

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**Supplementary Material:**

1. **Supplementary Table S1. Participating Facilities**
2. **Supplementary Table S2. Patient Questionnaire**
3. **Supplementary Table S3. Baseline demographics for participants of the qualitative research phase**

**Supplementary Table S1. Participating Facilities**

| The name of the facility | Location |
|---|---|
| Sendai Cardiovascular Center | Miyagi, Japan |
| Tohoku Kosai Hospital | Miyagi, Japan |
| Tokorozawa Heart Center | Saitama, Japan |
| Kawaguchi Cardiovascular and Respiratory Hospital | Saitama, Japan |
| Nerima General Hospital | Tokyo, Japan |
| Ushiku Aiwa General Hospital | Ibaraki, Japan |
| Kasugai Municipal Hospital | Aichi, Japan |
| Kanazawa Medical University Himi Municipal Hospital | Toyama, Japan |
| Public Central Hospital of Matto Ishikawa | Ishikawa, Japan |
| Hyogo Prefectural Nishinomiya Hospital | Hyogo, Japan |
| Japanese Red Cross Oita Hospital | Oita, Japan |
| Japanese Red Cross Nagasaki Genbaku Hospital | Nagasaki, Japan |
| Naha Municipal Hospital | Okinawa, Japan |

**Supplementary Table S2. Patient questionnaire**

| Question group | No. | Question |
|---|---|---|
| Information of the person who fills in | 1 | Who will be filling in the answers to this survey?<br>Note: All questions are asked to the patient. If a family member, a relative, or a caregiver helps to fills in, please ask the patient his/her answers and do fill-in only.<br>1. I am the patient.<br>2. I am a family member or a relative of a patient.<br>3. I am a carer of a patient. |
| Patient demographics | 2 | What is your gender?<br>1. Male<br>2. Female<br>3. Non-binary |

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| | | 4. Do not want to answer |
| | 3 | What is your age group?<br>1. 18–29 years<br>2. 30–39 years<br>3. 40–49 years<br>4. 50–-59 years<br>5. 60–69 years<br>6. 70–79 years<br>7. 80–89 years<br>8. 90 years or older |
| | 4 | In which region are you living currently?<br>1. Hokkaido and Tohoku<br>2. Kanto and Koshinetsu<br>3. Tokai and Hokuriku<br>4. Kinki<br>5. Chugoku and Shikoku<br>6. Kyushu and Okinawa |
| | 5 | What is your current employment status? If you are not working, please enter 0.<br>I work < > days a week. |
| | 6 | What is your final education?<br>1. Elementary or middle school<br>2. High school<br>3. Vocational school, technical college, or junior college<br>4. University<br>5. Graduate school<br>6. Others < please specify > |
| Condition of HF | 7 | How long have you been diagnosed with heart failure?<br>1. <1 year<br>2. 1 to <5 years<br>3. 5 to <10 years |

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| | | 4. 10 years or more<br><br>5. Do not know |
| | 8 | How long since you started treatment for heart failure?<br><br>1. <1 year<br><br>2. 1 to <5 years<br><br>3. 5 to <10 years<br><br>4. 10 years or more<br><br>5. Do not know |
| | 9 | Have you received any of the following explanations from your treating physician regarding your heart failure?<br><br>1. The heart's ability to pump blood (or the heart's ability to contract) is reduced.<br><br>2. The heart's ability to draw blood (or the heart's ability to have blood back) is reduced.<br><br>3. Neither of the above<br><br>4. Received no explanation<br><br>5. Do not know |
| | 10 | The following is a classification of the severity of heart failure into I to IV based on the patient's subjective symptoms. Which is most applicable to your current situation?<br><br>1. I: Physical activity is not particularly limiting. Routine physical activity (e.g., laundry, cleaning, stretching) does not produce symptoms such as fatigue, palpitations, dyspnea, or anginal pain.<br><br>2. II: No symptom at rest or during light physical activity, but relatively high exertion (e.g., stair ascent, hill walking) can cause symptoms such as fatigue, palpitations, dyspnea, or anginal pain.<br><br>3. III: No symptoms at rest, but relatively mild exertion (such as reading or talking) can cause symptoms such as fatigue, palpitations, dyspnea, or anginal pain.<br><br>4. IV: Even at rest, there are symptoms such as fatigue, palpitations, dyspnea, or angina pain, and slight exertion can increase symptoms. |

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| | 11 | Have you heard from a physician about a cause of your heart failure?<br>1. Yes<br>2. No<br>3. Do not know |
| | 12 | (If answered “yes” in Question 11)<br>What have you heard from a physician as a cause of your heart failure? Please choose all that apply.<br>1. Hypertension<br>2. Valvular disease<br>3. Myocardial infarction<br>4. Arrhythmias<br>5. Cardiomyopathy (abnormality in cardiac muscle strength)<br>6. Congenital heart disease<br>7. Others < please specify > |
| | 13 | Have you been hospitalized for the treatment of heart failure? How many times have you had hospital admissions?<br>1. None<br>2. Once<br>3. 2–3 times<br>4. 4–5 times<br>5. 6 times or more |
| | 14 | Have you had any heart procedure such as surgery?<br>1. Yes<br>2. No<br>3. Do not know |
| | 15 | (If answered “yes” in question 14)<br>Please tell me the details of the actions you have experienced. Please choose all that apply.<br>**Treatment of the blood vessels (coronary arteries) of the heart**<br>1. Catheter |

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| | | 2. Surgery (coronary artery bypass surgery)<br>3. Do not know<br>**Treatment of heart valves**<br>1. Catheter<br>2. Surgery (valvuloplasty, valve replacement)<br>3. Do not know<br>4. Pacemaker<br>5. Others < please specify > |
| Complications | 16 | Do you have any disease that is being treated other than heart failure?<br>1. Yes<br>2. No<br>3. Do not know |
| | 17 | What are your diseases being treated other than heart failure? Please choose all that apply.<br>1. Hypertension<br>2. Diabetes mellitus<br>3. Chronic kidney disease<br>4. Dyslipidemia<br>5. Cerebral infarction<br>6. Obesity disease<br>7. Depression<br>8. Dementia<br>9. Others < please specify > |
| | 18 | (If answered “yes” in Question 16)<br>Which of the diseases being treated is the most burdensome?<br>1. Heart failure<br>2. Hypertension<br>3. Diabetes mellitus<br>4. Chronic renal disease |

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| | | 5. Dyslipidemia<br>6. Cerebral infarction<br>7. Obesity<br>8. Depression<br>9. Dementia<br>10. Others < please specify > |
| Patient pathway to HF treatment | 19 | How long have you had a heart failure symptom before you first visited a medical institute for that symptom?<br>1. <1 week<br>2. 1 week to <1 month<br>3. 1 to <6 months<br>4. 6 months to <1 year<br>5. 1 year to <3 years<br>6. 3 years or more<br>7. Do not know |
| | 20 | (If one month or more in Question 19)<br>What is the reason you did not come to see immediately?<br>1. Because I did not think I had heart failure (I thought it was due to age, busyness, stress, etc.).<br>2. Because the symptoms were not severe enough to consult a physician.<br>3. I didn't know which medical institution I should go to.<br>4. Others < please specify > |
| | 21 | Which medical institution did you see for the first time with a symptom that appeared to be heart failure?<br>1. General practitioner<br>2. General hospital<br>3. Cardiovascular hospital<br>4. University hospital<br>5. Do not know |
| | 22 | How long have you been until you started to receive treatment for heart failure since you first visited a medical institute for a symptom that appeared to be heart failure? |

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| | | 1. Immediately on the same day<br>2. Next day to <1 week<br>3. 1 week to <1 month<br>4. 1 to <6 months<br>5. 6 months to <1 year<br>6. 1 year or more<br>7. Do not know |
| Physical and emotional burdens associated with HF | 23 | Do you feel burdened by each of the following activities since you had heart failure? Please assess each of the followings with one of the three levels (not burdened, burdened, fairly burdened). If you do not know it, please choose "do not know". If you usually do not do it, please choose “do not do”.<br>1. Change clothes alone<br>2. Wash face and brush teeth<br>3. Hang laundry<br>4. Vacuum<br>5. Clean a bath<br>6. Carry shopping bags<br>7. Walk fast or run a little<br>8. Go up the stairs to the second floor<br>9. Do gardening (weeding)<br>10. Do light farming<br>11. Take a shower<br>12. Take a bath<br>13. Lay down futon by yourself<br>14. Lie asleep |
| | 24 | Assuming your hypothetical level of burden of heart failure in daily life just before you started treatment for heart failure was 5 on a scale of 0 to 10, what is the level of your current burden, where 0 is “no burdensome at all at present”, 5 is “no difference from just before I started treatment for heart failure”, and 10 is “much more burdensome compared to just before I started treatment for heart failure”? |

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| | | Level < > |
| | 25 | How emotionally burdensome is it for you living with heart failure?<br>1. Fairly<br>2. Somehow<br>3. Slightly<br>4. Little<br>5. No |
| | 26 | (Only if answered “fairly” or “somehow” in question 25)<br>Which of the followings are your emotional burdens? Please choose all that apply.<br>1. Current medical conditions and anxiety in daily life<br>2. Course of the disease and anxiety for future<br>3. Anxiety or dissatisfaction about treatment<br>4. Anxiety or dissatisfaction about physicians or other healthcare professionals<br>5. Anxiety or dissatisfaction about family members and people around<br>6. Anxiety about what we often don't know about the disease or treatment<br>7. Anxiety about financial burden<br>8. Others < please specify > |
| | 27 | (If answered "anxiety or dissatisfaction about treatment" or "anxiety or dissatisfaction about physicians or other healthcare professionals " in Question 26)<br>Please explain specifically what causes your emotional burdens.<br>< please specify > |
| | 28 | (If answered “little” or “no” in question 25)<br>What are the reasons you don't feel any emotional burden? Please choose all that apply.<br>1. Because no particular physical symptom after diagnosed with heart failure. |

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| | | 2. Because I see reliable physicians and other healthcare professionals.<br><br>3. Because I am in an environment where I can get support in my daily life (e.g., from family or nursing service).<br><br>4. Because I have a good understanding of the disease.<br><br>5. Others < please specify > |
| | 29 | Assuming your hypothetical level of emotional burden of heart failure in daily life just before you started treatment for heart failure was 5 on a scale of 0 to 10, what is the level of your current burden, where 0 is “no burdensome at all at present”, 5 is “no difference from just before I started treatment for heart failure”, and 10 is “much more burdensome compared to just before I started treatment for heart failure”?<br><br>Level < > |
| Information of disease | 30 | Since you had heart failure, have you wanted information related to heart failure and its treatment?<br><br>1. Yes<br><br>2. No<br><br>3. Do not know |
| | 31 | (When answered “yes” in question 30)<br><br>How have you obtained information related to heart failure and its treatment? Please choose all that apply.<br><br>1. Via explanation of a physician and/or a healthcare professional<br><br>2. Via booklets and/or brochures provided by a physician and/or healthcare professionals<br><br>3. Via internet, books, etc. at my effort<br><br>4. Via support of my family and/or people around me<br><br>5. Others < please specify ><br><br>6. Did not obtain |
| | 32 | (If answered “no” in question 30)<br><br>What was the reason you did not want information related to heart failure and its treatment? Please choose all that apply.<br><br>1. Because heart failure did not seem to affect my life. |

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| | | 2. Because my symptoms were improved with treatment.<br>3. Because I relied on the physician.<br>4. Because I thought nothing would change in particular even if I obtained information.<br>5. Others < please specify > |
| | 33 | (If answered “via internet, books, etc. at my effort” in Question 31)<br>When did you search information related to heart failure? Please choose all that apply.<br>1. When symptoms first appeared<br>2. When I first visited a hospital<br>3. When I started treatment for heart failure<br>4. When I experienced my symptoms progressed<br>5. Others < please specify > |
| | 34 | What were the keywords did you use to look for information related to heart failure?<br>< Please write the keywords > |
| | 35 | (If answered “via booklets and/or brochures provided by a physician and/or a healthcare professional” in question 31)<br>To what extent have you read the booklets and/or brochures you received?<br>1. Thoroughly<br>2. Somewhat<br>3. Little<br>4. Not at all<br>5. Do not know |
| | 36 | Do you want to know more about heart failure and its treatment at present?<br>1. Yes<br>2. No<br>3. Do not know |
| | 37 | (When answered “yes” in question 36) |

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| | | What information do you think is good for treating heart failure? Please choose all that apply.<br>1. Treatment<br>2. Examinations<br>3. Diet and nutrition management<br>4. Exercise<br>5. Tips in daily life to avoid burden on my heart<br>6. Smoking cessation<br>7. Stress management<br>8. Others < please specify > |
| | 38 | Is there anything you have been informed by a physician or a healthcare professional that you need to do routinely in relation to the treatment of heart failure? Please choose all that apply. If nothing was informed, please choose “none in particular”.<br>1. Take medicine as instructed<br>2. Eat a low-sodium diet<br>3. Pay attention to water intake<br>4. Eat a well-balanced diet<br>5. Measure body weight routinely<br>6. Measure blood pressure routinely<br>7. Refrain from smoking<br>8. Refrain from alcohol consumption<br>9. Do exercise moderately<br>10. Get a flu vaccination<br>11. Avoid stresses<br>12. Contact a hospital, physician, or nurse when your physical condition or body weight changes<br>13. Refrain from going out and contacting others as much as possible because of the COVID-19 pandemic<br>14. Others <please specify ><br>15. None in particular |

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| Self-care and support for<br><br>treatment in daily life | 39 | Is there anything you have been working on or caring routinely? Please choose all that apply. If nothing has been worked on or cared, please choose “none in particular”.<br><br>1. Take medicine as instructed<br><br>2. Eat a low-sodium diet<br><br>3. Pay attention to water intake<br><br>4. Eat a well-balanced diet<br><br>5. Weigh my body routinely<br><br>6. Measure blood pressure routinely<br><br>7. Refrain from smoking<br><br>8. Refrain from alcohol consumption<br><br>9. Do exercise moderately<br><br>10. Get a flu vaccination<br><br>11. Avoid stresses<br><br>12. Contact a hospital, physician, or nurse when your physical condition or body weight changes<br><br>13. Refrain from going out and contacting others as much as possible because of the COVID-19 pandemic<br><br>14. Others < please specify ><br><br>15. None in particular |
| | 40 | Who actively supports and helps you treat heart failure? Please choose all that apply. If there is no one, please choose “no one in particular "<br><br>1. Physician<br><br>2. Healthcare professional other than physician (e.g., nurse, pharmacist, heart failure self-care advisor)<br><br>3. Family<br><br>4. Workplace<br><br>5. Friend<br><br>6. Patient with the same disease<br><br>7. Public administration<br><br>8. Others < please specify ><br><br>9. None in particular |

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| | 41 | Whom can you contact when you get your heart failure symptoms worsened? Please choose all that apply. If no one is there, please choose “no one in particular”.<br>1. Physician<br>2. Healthcare professional other than physician (e.g., nurse, pharmacist, heart failure self-care advisor)<br>3. Home helper<br>4. Family<br>5. Workplace<br>6. Friend<br>7. Others < please specify ><br>8. None in particular |
| Self-care and support for treatment in daily life | 42 | From whom would you like more support and help for your heart failure treatment? Please choose all that apply. If no one is there, please choose “no one in particular”.<br>1. Physician<br>2. Healthcare professional other than physician (e.g., nurse, pharmacist, heart failure self-care advisor)<br>3. Family<br>4. Supervisor or co-worker in the workplace<br>5. Friend<br>6. Patient with the same disease<br>7. Public administration<br>8. Others < please specify ><br>9. Not especially |
| Experience in clinical trial | 43 | Have you ever participated in a clinical trial of a drug?<br>1. Yes<br>2. No<br>3. Do not know |
| | 44 | (If answered “yes” in Question 43)<br>What burdens did you feel through trial participation? Please choose all that apply. If you think you had no burden, please choose “nothing in particular”. |

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| | | 1. Anxiety about the efficacy and side effects of the study drug<br>2. No other drugs allowed to use while participating in the trial<br>3. Number of consultations increased<br>4. Number of blood sampling and examinations increased<br>5. A long waiting time in the hospital for consultation and examinations<br>6. Medical expense increased<br>7. Daily life restricted<br>8. No continued use of the study drug after the trial completed<br>9. Anxiety about personal information protection<br>10. Others < please specify ><br>11. None in particular |
| | 45 | (if answered "yes" in Question 43)<br>What benefits did you receive through trial participation? Please choose all that apply. If you think you received no benefit, please choose “nothing in particular”.<br>1. My disease condition improved<br>2. Contribution to the development of a new drug<br>3. Good consultation with the investigator about my disease and treatment<br>4. Good support by the clinical trial coordinator<br>5. My knowledge of the disease and treatment increased<br>6. Treatment I was satisfied with<br>7. Care I preferentially received<br>8. Medical and logistic expenses reduced<br>9. Others < please specify ><br>10. None in particular |

**Supplementary Table S3. Baseline demographics for participants of the qualitative research phase**

| Demographic | n (%) |
|---|---|
| **Age, years (n=15)** | |
| 18 to 29 | 0 (0.0) |
| 30 to 39 | 1 (6.7) |
| 40 to 49 | 2 (13.3) |
| 50 to 59 | 0 (0.0) |
| 60 to 69 | 5 (33.3) |
| 70 to 79 | 7 (46.7) |
| 80 to 89 | 0 (0.0) |
| ≥ 90 | 0 (0.0) |
| **Gender (n=15)** | |
| Male | 12 (80.0) |
| Female | 3 (20.0) |
| **HF severity* (n=15)** | |
| No symptoms | 5 (33.3) |
| Mild symptoms | 9 (60.0) |
| Moderate symptoms | 1 (6.7) |
| Severe symptoms | 0 (0.0) |
| **Time since HF diagnosis, years (n=15)** | |
| < 1 | 2 (13.3) |
| ≥ 1 to < 5 | 3 (20.0) |
| ≥ 5 to < 10 | 6 (40.0) |
| ≥ 10 | 4 (26.7) |
| **Cause of HF (n=15)** | |
| Hypertension | 5 (33.3) |
| Valvular disease | 0 (0.0) |
| Myocardial infarction | 2 (13.3) |
| Arrhythmia | 4 (26.7) |
| Cardiomyopathy | 2 (13.3) |
| Congenital heart disease | 0 (0.0) |
| Other | 2 (13.3) |
| **Prior HHF (n=15)** | |
| 0 times | 3 (20.0) |
| 1 time | 8 (53.3) |
| 2 to 3 times | 2 (13.3) |
| 4 to 5 times | 0 (0.0) |
| ≥ 6 times | 2 (13.3) |

*Participants were asked to categorize the severity of their HF, based on the descriptions of the NYHA classification of severity of HF.

HF, heart failure; HHF, hospitalization for HF; NYHA, New York Heart Association.