

# Questionnaire on Advance Care Planning for patients with heart failure

(Nurse version)

## Definition of “Advance Care Planning (ACP)” in this study

ACP is described as the overall process of discussing the wishes of patients and their families for specific treatments and living arrangements, which should be discussed with medical staff before patients’ decision-making ability is impaired.

The following topics concerning ACP are considered in this questionnaire:

- Where and how to spend end-of-life stages;
- Whether patients want cardiopulmonary resuscitation, wearing a ventilator, or dialysis when their medical condition worsens;
- Whether or not patients wish to use sedative or narcotics when their condition worsens;
- Whether or not to deactivate the function of implantable cardioverter-defibrillator (ICD) or cardiac resynchronization therapy defibrillator (CRT-D) at the time of medical condition deterioration.

## ■ Target respondents of this questionnaire

Participants of this study are cardiologists and nurses who belong to certified institutions for ICD and/or CRT and manage a high number of heart failure cases annually. Participants were also recommended by the cardiology department director and the director of nursing.

## ■ Questionnaire contents

This questionnaire asks about the perceptions of cardiologists and nurses regarding ACP for patients with heart failure. The questionnaire contains six pages and requires approximately 15 minutes to complete.

## ■ Questionnaire collection

After completing the questionnaire, please send it back to the research team in a closed envelope. We expect to receive your responses within 10 days after the survey is delivered.

In order to maintain the confidentiality of your personal information, please do not include your address or name on the questionnaire or on the reply envelope.

If you have any questions or comments, please contact the person in charge of the survey mentioned below:

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If you understand the purpose of this survey and you agree to participate, please circle “I agree.”

I agree.

I don’t agree.

1. Please circle the option that best describes your institution:

1) Number of hospital beds

(1) 20 - 99	(2) 100 - 199	(3) 200 - 399	(4) 400 or more
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2) Please circle the answer that applies to your institution for each of the following items:

Items	Answer	
(1) Is a cardiovascular center	Yes	No
(2) Is an advanced treatment hospital	Yes	No
(3) Has a coronary care unit	Yes	No
(4) Is a certified institution for ventricular assist devices	Yes	No
(5) Is a certified institution for transcatheter aortic valve implantation	Yes	No
(6) Is a certified institution for heart transplantation	Yes	No
(7) Has a palliative care team	Yes	No
(8) Has multidisciplinary care conferences for patients with heart failure	Yes	No
(9) Has certified nurses in chronic heart failure nursing	Yes	No
(10) Has certified nurses in palliative care	Yes	No
(11) Has nurse-led outpatient care for patients with heart failure	Yes	No

2. Please provide the following information about yourself. Circle the option that best describes your response.

1) Sex

(1) Male	(2) Female
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2) Age

(1) Less than 30 years/30s	(2) 40 – 49 years	(3) 50 – 59 years	(4) 60 years or more
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3) Clinical experience

(1) 0 – 4 years	(2) 5 – 9 years	(3) 10 – 14 years
(4) 15 – 19 years	(5) 20 – 24 years	(6) More than or equal to 25

4) Experience in cardiology ward

(1) 0 – 4 years	(2) 5 – 9 years	(3) 10 – 14 years
(4) 15 – 19 years	(5) 20 – 24 years	(6) More than or equal to 25

5) Position

(1) Staff	(2) Chief or leader	(3) Vice head nurse	(4) Head nurse
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6) Qualification

(1) Certified Nurse in Chronic Heart Failure Nursing	(2) Certified Nurse Specialist in Critical Care Nursing	(3) Certified Nurse Specialist in Chronic Care Nursing
(4) Others: (		)

7) In the past month, how many hospitalized patients with heart failure who meet the following conditions or timings were you in charge of? Please circle the number that best describes your response.

Number of patients	0	1-4	5-10	11-15	16-20	21 or more
Condition or timing						
(1) Patients diagnosed as heart failure for the first time	1	2	3	4	5	6
(2) Patients with left ventricular ejection fraction $\leq 20$ when hospitalized	1	2	3	4	5	6
(3) Patients in the New York Heart Association functional class IV and requiring frequent/continuous infusion pharmacotherapy	1	2	3	4	5	6
(4) Patients with cardiac resynchronization therapy-defibrillator implantation	1	2	3	4	5	6
(5) Patients with ventricular assist device	1	2	3	4	5	6
(6) Patients registered for heart transplantation	1	2	3	4	5	6
(7) Patients clinically judged to be close to end-of-life stages	1	2	3	4	5	6

3. Please imagine the condition or timing of patients with heart failure for each item found below and answer the following question:

To what extent should the multi-disciplinary team discuss with patients “whether they want cardiopulmonary resuscitation, wearing a ventilator, or dialysis when their medical condition worsens?”

Please circle the number that best describes your response.

Degree of implementation	ACP must not be implemented	ACP should not be implemented	Not sure	ACP should be implemented	ACP must be implemented
Condition or timing					
1) Patients diagnosed as heart failure for the first time	1	2	3	4	5
2) Patients hospitalized for the first time	1	2	3	4	5
3) Patients with a record of hospitalization more than twice a year	1	2	3	4	5
4) Patients requiring nearly all types of care for daily life due to deterioration of physical/mental functions	1	2	3	4	5
5) Patients with left ventricular ejection fraction $\leq 20$ when hospitalized	1	2	3	4	5
6) Patients in New York Heart Association functional class IV and requiring frequent/continuous infusion pharmacotherapy	1	2	3	4	5
7) Patients with cardiac resynchronization therapy-defibrillator implantation	1	2	3	4	5
8) Patients with ventricular assist device	1	2	3	4	5
9) Patients registered for heart transplantation	1	2	3	4	5
10) Patients clinically judged to be close to end-of-life stages	1	2	3	4	5

4. Please think about a patient with heart failure in the following scenario:

A housebound 68 years old patient with advanced CHF (NYHA class IV symptoms at baseline, LVEF=20% with an CRT-D in place), who requires assistance for most activities of daily living, is admitted to the cardiology ward under your care with an exacerbation of his/her CHF. The patient’s acute symptoms have been resolved. You are uncertain about the patient’s goals of care and preferences regarding the use (or non-use) of life-sustaining technology.

During the hospitalization of this patient, to what extent the multidisciplinary team (including physicians, nurses, physiotherapists, social workers, and other health professionals) should implement the following ACP actions for this patient. Please circle the number that best describes your response.

Degree of implementation  ACP actions	It must not be implemented	It should not be implemented	Not sure	It should be implemented	It must be implemented
1) Ask patient about how he/she perceives the heart failure progression	1	2	3	4	5
2) Ask patient about what has been important in life so far	1	2	3	4	5
3) Ask patient about what kind of life he/she would like to live from now on	1	2	3	4	5
4) Ask patient to what extent he/she would like to know about treatment in the following days/months	1	2	3	4	5
5) Ask patient whom he/she would prefer to help them in making decisions when he/she becomes unable to do so	1	2	3	4	5
6) Ask patient if he/she wishes to know about his/her functional prognosis and life expectancy	1	2	3	4	5
7) Provide predictions concerning functional prognosis and life expectancy	1	2	3	4	5
8) Ask about patient’s wish concerning cardiopulmonary resuscitation	1	2	3	4	5
9) Ask about patient’s wish concerning the use of narcotic analgesics when acute aggravation occurs	1	2	3	4	5
10) Ask about patient’s wish concerning sedation when acute aggravation occurs	1	2	3	4	5
11) Ask about patient’s wish concerning life-prolonging medical treatments such as the use of hemodialysis or ventilator when acute aggravation occurs	1	2	3	4	5
12) Ask about patient’s wish concerning the place where he/she wishes to be at the end of life	1	2	3	4	5
13) Ask about patient’s wish concerning deactivation of cardiac resynchronization therapy-defibrillator	1	2	3	4	5

5. Please let us know what do you usually experience when providing ACP for patients with heart failure.  
Please circle the number that best describes your response.

Situation	Degree of agreement				
	Strongly disagree	Disagree	Not sure	Agree	Strongly agree
1) Patients cannot accept their poor prognosis	1	2	3	4	5
2) Patients do not understand life-prolonging medical treatments that may be happening in the future	1	2	3	4	5
3) Family members cannot accept patients' poor prognosis	1	2	3	4	5
4) Family members do not understand life-prolonging medical treatments that may be happening in the future	1	2	3	4	5
5) There is disagreement regarding care goals among family members	1	2	3	4	5
6) The prognosis is difficult to predict	1	2	3	4	5
7) Medical staff desires to do whatever possible for prolonging patients' lives	1	2	3	4	5
8) Medical staff wishes to give hope to patients and their families	1	2	3	4	5
9) Medical staff does not have time to implement ACP for patients and their families	1	2	3	4	5
10) Medical staff does not know how to implement ACP for patients and their families	1	2	3	4	5
11) There is disagreement regarding care goals among team members of the same profession	1	2	3	4	5
12) There is disagreement regarding care goals among team members of different professions	1	2	3	4	5

- Feel free to describe how do you feel in your daily work regarding ACP for patients with heart failure and their family members.

Thank you for your participation in this survey.