

Supplemental Appendix for:

Current Status of Advance Care Planning and End-of-life Communication for Patients with Advanced and Metastatic Breast Cancer

Yasuaki Sagara et al.

Supplement 1. Questionnaire concerning the current status of advance care planning for patients with advanced and metastatic breast cancer

Facility type and function

- 1. Name of facility
- 2. Type of facility
 - University hospital
 - o Cancer center
 - o National hospital organization
 - Prefectural and municipal hospitals
 - Medical corporation
 - o Other (please specify)
- 3. Is your facility a designated hospital for cancer treatment and care?
- 4. Does your facility consist of a supportive/palliative care clinic?
- 5. Does your facility consist of a palliative care ward?
- 6. Does your facility have a palliative care team?

Physicians' background

- 7. Department
 - Breast surgical oncology
 - Medical oncology

- Palliative care
- Other (please specify)
- 8. Board certification
 - o Japan Breast Cancer Society
 - o Japanese Board of Cancer Therapy
 - Japanese Society of Medical Oncology
 - Other (please specify)
- 9. Year of experience in cancer treatment
 - o < 5 years
 - o 5–9 years
 - o 10–19 years
 - $\circ \geq 20 \text{ years}$

Physicians' clinical practice situation and their resource use for patients with metastatic and recurrent cancer

- 10. Average number of outpatients in charge per day
 - o No outpatient consultation
 - o 1–4 patients
 - o 5–9 patients
 - o 10–19 patients
 - o 20–39 patients
 - $\circ \geq 40$ patients
- 11. Average number of patients with metastatic/advance breast cancer in charge per week (including outpatient and inpatient)
 - o No consultation of patients with metastatic/advance breast cancer

- o 1–4 patients
- o 5–9 patients
- o 10–19 patients
- o 20–39 patients
- $\circ \geq 40$ patients
- 12. Average consultation time with outpatients with metastatic/advance breast cancer
 - o < 10 minutes
 - o 10–29 minutes
 - \circ \geq 30 minutes
- 13. When is appropriate timing for referring the patients to a palliative care department? Please choose two main timings in your clinical practice.
 - As soon as possible after the diagnosis of metastasis, even without any symptoms
 - o The patient needs psychological support
 - o Poor pain control of the patient
 - o Late line (e.g., 4th or 5th line) of anticancer therapy
 - Before withdrawal of anticancer therapy, or before transfer to the palliative care ward
- 14. Do you regularly conduct a screening of physical and mental distress for outpatient?

Opportunity for education about end-of-life communication

15. Does your facility have an official advance care planning or communication workshop for healthcare professionals (doctors, nurses, multi-professions); for example, PEACE, SHARE, ELNEC-J, E-FIELD, etc.?

16. Have you ever participated in an official advance care planning or communication workshop for healthcare professionals (doctors, nurses, multi-professions); for example, PEACE, SHARE, ELNEC-J, E-FIELD, etc.?

Physicians' understanding of advance care planning

- 17. Do you comprehend what advance care planning means?
 - Well understood
 - Almost understood
 - I have heard the word
 - Never heard
- 18. The following four sentences show the definition of advance care planning in each organization. Which one is closest to the definition of advance care planning you consider?
 - I. A process of discussion of end-of-life care, clarification of related values and goals, and embodiment of preferences through written documents (e.g., advance directive, physicians' orders for life-sustaining treatment) and medical orders
 - II. A process in which the individual repeatedly discusses end-of-life treatment and care with the family and care teams in advance
 - III. Advance care planning is a process that supports adults, at any age or stage of health, in understanding and sharing their personal values, life goals, and preferences regarding future medical care
 - IV. Advance care planning enables individuals to define goals and preferences for future medical treatment and care, to discuss these goals and preferences with family and health-care providers, and to record and review these preferences if appropriate

- 19. Do you consider that the process of advance care planning is necessary in your clinical practice?
- 20. Are you engaged in advance care planning? If not, please specify why.

Current situation of advance care planning in clinical practice

- 21. Who takes the initiative to provide advance care planning in your healthcare organization?
 - o The entire healthcare organization (i.e., multi-professional team)
 - o Breast surgical oncology or medical oncology department
 - o Palliative care department
 - o Nursing department
 - o Not performed organizationally, but by individual medical staff
- 22. Do you use a pamphlet about advance care planning or a structured format to facilitate the conversation?
- 23. Do you or your institution develop triggers or sentinel events (e.g. initial diagnosis of metastatic disease, relapse or progression) for the initiation of advance care planning?
- 24. Does your institution have a system to consider the appropriate process of advance care planning or end-of-life discussions? (e.g., cross-organizational team offering conference and consultant)
- 25. How often do nurses intervene (discussing patients' medical condition, treatment, etc.) when a patient with advanced/metastatic breast cancer visits the outpatient clinic?
 - Every time
 - Almost every time
 - o Appropriate time according to patients' condition

- Never
- 26. Is it possible to cooperate with consultants (nurses and social workers) who have received advance care planning training (e.g., E-FIELD)?
- 27. Is it possible to cooperate with consultants (nurses and social workers) who have not received advance care planning training (e.g., E-FIELD)?
- 28. Does your facility introduce a national system that supports patients' lives, such as nursing care insurance and disability pensions?
- 29. Do you discuss with patients about their concerns, values, life goals, and their preference for future care?
 - o All patients
 - Almost all patients
 - Sometimes
 - Rarely
 - Never
- 30. Please choose one timing for the discussion with patients
 - o As soon as possible after the diagnosis of advanced/metastatic breast cancer
 - When the physical symptom(s) appears
 - o When the expected prognosis is less than one year
 - o When the number of remaining anticancer therapy is few
 - When the patient is hospitalized by worsening of physical symptom(s) and performance status
 - o When the patient and/or family ask the physician a relevant topic
- 31. How do you discuss with the patient?
- 32. Please let us know if you have decided or devised a method of discussion.

33. At your facility, what do you think is a barrier to patients with a non-curable disease from receiving medical treatment and care concordant with their goals and values?

Cı

urrent situation of end-of-life discussion in clinical practice			
34.	4. Do you discuss with patients' life expectancy with them?		
	0	All patients	
	0	Almost all patients	
	0	Sometimes	
	0	Rarely	
	0	Never	
35.	Do yo	Oo you discuss patients' future physical functioning with them?	
	0	All patients	
	0	Almost all patients	
	0	Sometimes	
	0	Rarely	
	0	Never	
36.	Do yo	ou discuss preferred end-of-life medical care with patients and their families?	
	0	All patients and families	
	0	Almost all patients and families	
	0	Sometimes	
	0	Rarely	
	0	Never	
37.	To wl	hat extent do you document patients' concerns, values, goals in life, discussions	
	about	future medical care intentions and prognosis, and discussions about end-of-life	
	care,	care, etc. in your medical chart?	

- o Mostly not documented
- o Documented as a brief summary
- o Document the content of discussion in detail
- Other (please specify)
- 38. How do you share the patient/family member discussions with your medical staff?
- 39. How do you share the patient discussions with their family members?