

I Respondant profile.

1)Age ()y.o.

2)Sex 1. Male 2. Female

3)Place of Work

1. University Hospital 2. Children's Hospital 3. Rehabilitation centre
4. Other Hospital 5. Clinic
6. Other ()

4)Postgraduate experience ()yr

5)Specaility

1. Pediatric Neurology 2. Pediatric Hemmatology/Oncology 3. Internist
4. Other ()

6)Number of dying patients cared for

1. 0 2. 1~4 3. 5~9 4. 10~19
5. 20~29 6. 30+

7)Number of dying patients <18 years of age cared for

1. 0 2. 1~4 3. 5~9 4. 10~19
5. 20~29 6. 30+

© The following questions refer to your experience with caring for life-threatening adolescent patients (13-18y.o.) with decision making capacity.

1) Do you have experience to care for life-threatening adolescent patients (13-18y.o.) with decision making capacity?

1. Yes



Go to Question II

2. No



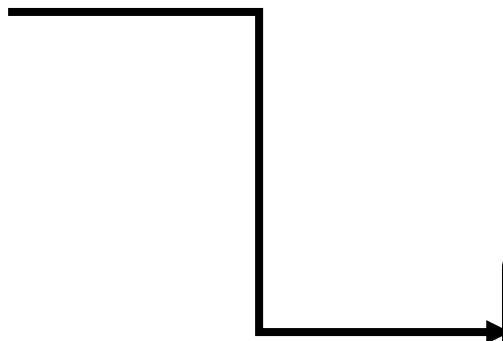
2) Do you have experience to care for life-threatening adolescent patients (13-18y.o.) without decision making capacity?

1. Yes



Go to Question III

2. No



Go to Question IV

II The following questions refer to your experience with advance care discussions with life-threatening adolescent patients (13-18y.o.) with decision making capacity.

In your experience, how often do you address with patients about the following topics if the patient's prognosis is over 1 year?

	never	rarely	sometimes	often	always
1 . Discuss medical condition	1	2	3	4	5
2 . Verify understanding of medical condition	1	2	3	4	5
3 . Discuss prognosis	1	2	3	4	5
4 . Discuss goals of treatment and care	1	2	3	4	5
5 . Promote sharing of treatment and care goals between patients and families	1	2	3	4	5
6 . Discuss where treatment and care will take place	1	2	3	4	5
7 . Discuss DNAR	1	2	3	4	5
8 . Discuss ventilator treatment if the patient's condition worsens	1	2	3	4	5

In your experience, how often do you address with patients about the following topics if the patient's prognosis is estimated less than 3month?

	never	rarely	sometimes	often	always
9 . Discuss medical condition	1	2	3	4	5
10. Verify understanding of medical condition	1	2	3	4	5
11. Discuss prognosis	1	2	3	4	5
12. Discuss goals of treatment and care	1	2	3	4	5
13. Promote sharing of treatment and care goals between patients and families	1	2	3	4	5
14. Discuss where treatment and care will take place	1	2	3	4	5
15. Discuss DNAR	1	2	3	4	5
16. Discuss ventilator treatment if the patient's condition worsens	1	2	3	4	5

The following questions refer to your experience with advance directives with life-threatening adolescent patients (13-18y.o.) with decision making capacity.

Do you address with patients about the following topics?

	No	Yes
17. Cardiopulmonary resuscitation	1	2
18. Use of ventilator	1	2
19. Use of vasopressor	1	2
20. Use of antibiotics	1	2
21. Use of tube-feeding	1	2
22. Use of intravenous fluids	1	2

III The following questions refer to your experience with advance care discussions with family of life-threatening adolescent patients (13-18y.o.) with decision making capacity.

In your experience, how often do you address with patients' families about the following topics if the patient's prognosis is over 1 year?

	never	rarely	sometimes	often	always
1 . Discuss medical condition	1	2	3	4	5
2 . Verify understanding of medical condition	1	2	3	4	5
3 . Discuss prognosis	1	2	3	4	5
4 . Discuss goals of treatment and care	1	2	3	4	5
5 . Promote sharing of treatment and care goals between patients and families	1	2	3	4	5
6 . Discuss where treatment and care will take place	1	2	3	4	5
7 . Discuss DNAR	1	2	3	4	5
8 . Discuss ventilator treatment if the patient's condition worsens	1	2	3	4	5

In your experience, how often do you address with patients' families about the following topics if the patient's prognosis is estimated less than 3month?

	never	rarely	sometimes	often	always
1 . Discuss medical condition	1	2	3	4	5
2 . Verify understanding of medical condition	1	2	3	4	5
3 . Discuss prognosis	1	2	3	4	5
4 . Discuss goals of treatment and care	1	2	3	4	5
5 . Promote sharing of treatment and care goals between patients and families	1	2	3	4	5
6 . Discuss where treatment and care will take place	1	2	3	4	5
7 . Discuss DNAR	1	2	3	4	5
8 . Discuss ventilator treatment if the patient's condition worsens	1	2	3	4	5

The following questions refer to your experience with advance directives with patients' families of life-threatening adolescent patients (13-18y.o.) with decision making capacity.

Do you address with patients' families about the following topics?

	No	Yes
17. Cardiopulmonary resuscitation	1	2
18. Use of ventilator	1	2
19. Use of vasopressor	1	2
20. Use of antibiotics	1	2
21. Use of tube-feeding	1	2
22. Use of intravenous fluids	1	2

IV In your experience, how often have the following issues served as barriers to discuss about advance care planning with adolescent patients (13-18y.o.) with decision making capacity ?

What is Advance Care Planning (ACP) ?

Advance care planning (ACP) is a voluntary process of discussion about future care among patients, their families, and health care providers

	Never	Rarely	Sometimes	Often	Always
1. Physician does not know the right time to address the issue	1	2	3	4	5
2. Physician does not know the things to say	1	2	3	4	5
3. Lack of physician time	1	2	3	4	5
4. Insufficient laws and guidelines	1	2	3	4	5
5. Ethical considerations	1	2	3	4	5
6. Lack of training	1	2	3	4	5
7. Physician uncertain about the prognosis	1	2	3	4	5
8. Physician considers ACP not that important	1	2	3	4	5
9. Differences in understanding the prognosis between physician and patient	1	2	3	4	5
10. Differences in understanding the prognosis between physician and family	1	2	3	4	5
11. Differences in understanding the prognosis between patient and family	1	2	3	4	5
12. Unrealistic physician expectations	1	2	3	4	5
13. Unrealistic patient expectations	1	2	3	4	5
14. Unrealistic family expectations	1	2	3	4	5
15. Physician not ready to have the discussion	1	2	3	4	5
16. Patient not ready to have the discussion	1	2	3	4	5
17. Family not ready to have the discussion	1	2	3	4	5
18. Patient unable to fully comprehend the issue	1	2	3	4	5
19. Family unable to fully comprehend the issue	1	2	3	4	5
20. Conflict between patient and parents	1	2	3	4	5
21. Conflict between parents and other family members	1	2	3	4	5
22. Physician concerned about losing the trust of the patient	1	2	3	4	5
23. Physician concerned about losing the trust of the family	1	2	3	4	5
24. No relationship between physician and patient	1	2	3	4	5
25. No relationship between physician and family	1	2	3	4	5
26. Physician concerned that the patient will receive less attention from physicians	1	2	3	4	5
27. Physician concerned that the family will receive less attention from physicians	1	2	3	4	5
28. Physician concerned about taking away patient's hope	1	2	3	4	5
29. Physician concerned about taking away family's hope	1	2	3	4	5