

## SUPPLEMENTAL MATERIAL

FAMILY CENTERED ADVANCE CARE PLANNING: SESSION 1  
THE LYON ADVANCED CARE PLANNING SURVEY  
RESULTS FOR ADOLESCENTS WITH HIV/AIDS, N=48  
PEDIATRIC PALLIATIVE CARE: QUALITY OF LIFE & SPIRITUAL STRUGGLE  
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### Advance Planning and Preparation

1. Have you ever written down any thoughts about your future health plans?

%	#	
19	9	Yes definitely
0	0	Very probably
2	1	Probably
4	2	Probably not
75	36	Definitely not
0	0	Don't know

2. Advance directives allow people to make their health care choices known before becoming very ill or dying.

- a. Have you ever heard about and completed a Health Care Power of Attorney (HCPA), in which you name someone to make decisions about your health care in case you could not?

%	#	
8	4	Have heard about and completed
19	9	Have heard about
67	32	Have not heard about
6	3	Don't know

- b. Have you ever heard about and completed an Advance Directive, such as Five Wishes?

%	#	
2	1	Have heard about and completed
23	11	Have heard about but not completed
73	35	Have not heard about
2	1	Don't know

3. a. Whether you have completed any advance directives/pre-plans or not, have you talked about your wishes for care at end of life with anyone? SELECT ALL THAT APPLY.

%	#	
4	2	Spouse/partner
27	13	Parents
10	5	Siblings (brother/sister)
8	4	Friends
10	5	Boyfriend/girlfriend
0	0	Lawyer
6	3	Primary Physician
2	1	Clergy (such a minister, rabbi, iman, etc.)
8	4	Other, (2 aunts, 1 grandmother, 1 order of my funeral, 1 social worker)
63	30	Have not talked with anyone

- 3.b. Do you have any children?

%	#	
8	4	Yes (proceed to question 3c)
92	44	No (proceed to question 4)

- 3.c. If you have children, have you talked about plans for who will take care of your child/children, if you are not able to? SELECT ALL THAT APPLY.

%	#	
2	1	Spouse/partner
4	2	Parents
0	0	Siblings
2	1	Friends
4	2	Boyfriend/Girlfriend
0	0	Lawyer
0	0	Primary Physician
0	0	Clergy
1	1	Other, please describe (no response recorded)

4. If you were ill and knew that you would not get better, who would you want to be involved in decision about your end-of-life care? SELECT ALL THAT APPLY.

%	#	
60	29	Myself
83	40	My Family
60	29	My Doctor
15	7	Someone else, please specify (3-boyfriend, 1-Dad, 1-my bishop, 1-my grandma because my family does not know my diagnosis, 1-my mother only, 1-not sure, 1-spouse/girlfriend, 1-surrogate)

5. When do you think it is the best time to bring up end-of-life decisions?

%	#	
38	18	While healthy
17	8	When first diagnosed with a life-threatening illness
4	2	When first sick from a life-threatening illness
8	4	When first hospitalized with a life-threatening illness
4	2	If dying
19	9	All of the above
10	5	Don't know

6. Who are the best people/person on the treatment team to bring it up with you? SELECT ALL THAT APPLY.

%	#	
56	27	Physician
33	16	Nurse Practitioner
27	13	Nurse
46	22	Social Worker
17	8	Psychologist
13	6	Case Manager
4	1	Chaplain
10	5	Patient Advocate
8	4	Other (2-Mom, 2-not sure)

7. Do you believe that once you make an important medical decision, for example, to be on a respirator, a machine that breathes for you, that you would be able to change your mind?

%	#	
29	14	Yes definitely
17	8	Very probable
25	12	Probably
10	5	Probably not
6	3	Definitely no
13	6	Don't know

8. Do you think your doctor or the hospital will respect your wishes, that is, do what you want about medical care?

%	#	
69	33	Yes definitely
19	9	Very probably
8	4	Probably
4	2	Probably not
0	0	Definitely not
0	0	Don't know

9. Do you think your parent/ guardian/ surrogate understands your wishes?

%	#	
58	28	Yes definitely
10	5	Very probably
15	7	Probably
13	6	Probably not
2	1	Definitely no
2	1	Don't know

10. Do you think your parent/guardian / surrogate will respect your wishes, that is, do what you want about your medical care?

%	#	
60	29	Yes definitely
8	4	Very probably
21	10	Probably
4	2	Probably not
6	3	Definitely no
0	0	Don't know

#### Thoughts about Death and Dying

11. How often has death and dying been talked about in your family?

%	#	
8	4	Very often
17	8	Often
15	7	Occasionally
42	20	Rarely
17	8	Never
2	1	Don't know

12. How comfortable are you talking about death?

%	#	
21	10	Very comfortable
21	10	Somewhat Comfortable
23	11	Neither comfortable or uncomfortable
21	10	Not very comfortable
8	4	Not at all comfortable
6	3	Don't know

13. How likely are you to...

- a. Attend funerals or memorial services when a loved one, friend or a classmate dies

%	#	
42	20	Very likely
38	18	Somewhat likely
2	1	Neither likely or unlikely
10	5	Not very likely
6	3	Not at all likely
2	1	Don't know

- b. Avoid medical checkups because you are afraid the doctor will find "something serious"

%	#	
6	3	Very likely
8	4	Somewhat likely
8	4	Neither likely or unlikely
23	11	Not very likely
50	24	Not at all likely
4	2	Don't know

- c. Speak freely to loved ones about death and dying

%	#	
23	11	Very likely
21	10	Somewhat likely
15	7	Neither likely or unlikely
10	5	Not very likely
27	13	Not at all likely
4	2	Don't know

- d. Visit or telephone a friend or relative who has recently lost a loved one in order to see how they are doing

%	#	
52	25	Very likely
33	16	Somewhat likely
6	3	Neither likely or unlikely
4	2	Not very likely
4	2	Not at all likely
0	0	Don't know

- e. Preplan your own funeral, for example, choose someone to speak or choose the music you would want

%	#	
40	19	Very likely
13	6	Somewhat likely
4	2	Neither likely or unlikely
17	8	Not very likely
17	8	Not at all likely
10	5	Don't know

14. How afraid if at all, are you of...

- a. Dying from a long term illness

%	#	
23	11	Very afraid
27	13	Somewhat afraid
8	4	Neither afraid nor not afraid
17	8	Not very afraid
21	10	Not at all afraid
4	2	Don't know

- b. Dying suddenly, such as an accident, or being killed

%	#	
38	18	Very afraid
29	14	Somewhat afraid
0	0	Neither afraid nor not afraid
15	7	Not very afraid
17	8	Not at all afraid
2	1	Don't know

- c. Dying alone

%	#	
23	11	Very afraid
15	7	Somewhat afraid
10	5	Neither afraid nor not afraid
15	7	Not very afraid
33	16	Not at all afraid
4	2	Don't know

d. Dying in an institution such as a nursing home or hospital

%	#	
15	7	Very afraid
13	6	Somewhat afraid
15	7	Neither afraid nor not afraid
15	7	Not very afraid
40	19	Not at all afraid
4	2	Don't know

e. Dying painfully

%	#	
44	21	Very afraid
27	13	Somewhat afraid
2	1	Neither afraid nor not afraid
4	2	Not very afraid
19	9	Not at all afraid
4	2	Don't know

15. How strongly do you agree or disagree that...

a. Dying is an important part of life

%	#	
50	24	Strongly agree
33	16	Agree
6	3	Neither agree or disagree
2	1	Disagree
2	1	Strongly disagree
6	3	Don't know

b. If someone could tell me when I would die, I would want to know

%	#	
27	13	Strongly agree
19	9	Agree
13	6	Neither agree or disagree
15	7	Disagree
19	9	Strongly disagree
8	4	Don't know

16. What you think about death and dying, how concerned are you that...

a. The family's money wont last

%	#	
15	7	Very concerned
33	16	Concerned
15	7	Neither concerned nor unconcerned
8	4	Not concerned
25	12	Not at all concerned
4	2	Don't know

b. I will be a burden, or overload, to my family or friends

%	#	
10	5	Very concerned
35	17	Concerned
6	3	Neither concerned nor unconcerned
19	9	Not concerned
17	8	Not at all concerned
13	6	Don't know

17. Which of the following health problems, if any, do you think are worse than death?

SELECT ALL THAT APPLY.

%	#	
44	21	Living with great pain
27	13	Total physical dependency on others, for example, being in a wheelchair
54	26	Not being able to communicate my wishes and/or care to family members, for example, being in a coma
33	16	None are worse than death

### Dealing with Dying

18. How important would each of the following be to you if you were dealing with your own dying?

a. Family and friends visiting you

%	#	
73	35	Very important
19	9	Somewhat important
4	2	Neither important nor unimportant
0	0	Not very important
2	1	Not at all important
2	1	Don't know



b. Being able to stay in your own home

%	#	
52	25	Very important
33	16	Somewhat important
0	0	Neither important nor unimportant
8	4	Not very important
4	2	Not at all important
2	1	Don't know

c. Honest answers from your doctor

%	#	
90	43	Very important
6	3	Somewhat important
4	2	Neither important nor unimportant
0	0	Not very important
0	0	Not at all important
0	0	Don't know

d. Comfort from church services or persons such as a minister, priest, imam, or rabbi

%	#	
35	17	Very important
29	14	Somewhat important
15	7	Neither important nor unimportant
6	3	Not very important
13	6	Not at all important
2	1	Don't know

e. Planning your own funeral

%	#	
38	18	Very important
30	14	Somewhat important
2	1	Neither important nor unimportant
6	3	Not very important
9	4	Not at all important
15	7	Don't know

f. Being able to complete an advance directive that would let your loved ones know your wishes, if you were unable to speak for yourself

%	#	
77	37	Very important
15	7	Somewhat important
2	1	Neither important nor unimportant
0	0	Not very important
6	3	Not at all important
0	0	Don't know

g. Fulfilling personal goals/ pleasures

%	#	
77	37	Very important
19	9	Somewhat important
0	0	Neither important nor unimportant
0	0	Not very important
0	0	Not at all important
4	2	Don't know

h. Reviewing your life history with your family

%	#	
46	22	Very important
35	17	Somewhat important
6	3	Neither important
6	3	Not very important
4	2	Not at all important
2	1	Don't know

i. Having health care professionals visit you at your home

%	#	
35	17	Very important
50	24	Somewhat important
6	3	Neither important nor unimportant
2	1	Not very important
4	2	Not at all important
2	1	Don't know

j. Understanding your treatment choices

%	#	
92	44	Very important
4	2	Somewhat important
2	1	Neither important nor unimportant
0	0	Not very important
0	0	Not at all important
2	1	Don't know

19. How important are each of the following to you when you think about dying?

a. Being physically comfortable

%	#	
75	36	Very important
15	7	Somewhat important
4	2	Neither important nor unimportant
0	0	Not very important
4	2	Not at all important
2	1	Don't know

b. Being free from pain

%	#	
88	42	Very important
8	4	Somewhat important
2	1	Neither important nor unimportant
0	0	Not very important
0	0	Not at all important
2	1	Don't know

c. Having said everything I want to say to people in my family

%	#	
79	38	Very important
15	7	Somewhat important
4	2	Neither important nor unimportant
2	1	Not very important
0	0	Not at all important
0	0	Don't know

d. Being at peace spiritually

%	#	
77	37	Very important
17	8	Somewhat important
2	1	Neither important nor unimportant
0	0	Not very important
4	2	Not at all important
0	0	Don't know

e. Not being a burden to loved ones

%	#	
56	27	Very important
31	15	Somewhat important
4	2	Neither important nor unimportant
2	1	Not very important
4	2	Not at all important
2	1	Don't know

f. Knowing how to say goodbye

%	#	
71	34	Very important
17	8	Somewhat important
4	2	Neither important nor unimportant
4	2	Not very important
0	0	Not at all important
4	2	Don't know

g. Having a sense of your own worth or value

%	#	
77	37	Very important
10	5	Somewhat important
4	2	Neither important nor unimportant
4	2	Not very important
2	1	Not at all important
2	1	Don't know

h. Being off machines that extend life such as life support

%	#	
35	17	Very important
35	17	Somewhat important
8	4	Neither important nor unimportant
4	2	Not very important
6	3	Not at all important
10	5	Don't know

i. Dying a natural death

%	#	
65	31	Very important
13	6	Somewhat important
6	3	Neither important nor unimportant
0	0	Not very important
2	1	Not at all important
15	7	Don't know

20. If death were likely to happen in the next few weeks, and you could choose where to die, where would you MOST want to die? CHECK ONE answer only.

%	#	
52	25	At home
0	0	In an assisted-living facility
13	6	In a hospital
0	0	In a nursing home
0	0	In a residential hospice
35	17	Don't know

21. Below are some statements related to pain near the end-of-life that have been expressed by people. How strongly do you agree or disagree with each statement?

a. I am afraid my doctor may not believe I am in pain and treat my pain

%	#	
13	6	Strongly agree
17	8	Agree
13	6	Neither agree nor disagree
23	11	Disagree
25	12	Strongly disagree
10	5	Don't know

b. I would only take pain medicines when the pain is severe

%	#	
31	15	Strongly agree
33	16	Agree
6	3	Neither agree or disagree
15	7	Disagree
8	4	Strongly disagree
6	3	Don't know

c. I will become addicted to pain medicines over time

%	#	
4	2	Strongly agree
4	2	Agree
17	8	Neither agree or disagree
31	15	Disagree
35	17	Strongly disagree
8	4	Don't know

d. I will take low dose and save large dose for when pain is worse

%	#	
27	13	Strongly agree
27	13	Agree
4	2	Neither agree nor disagree
17	8	Disagree
8	4	Strongly disagree
17	8	Don't know

e. Youth will be given too much pain medicine

%	#	
4	2	Strongly agree
31	15	Agree
15	7	Neither agree or disagree
23	11	Disagree
19	9	Strongly disagree
8	4	Don't know

22. Have you heard of hospice services?

%	#	
73	35	Yes
27	13	No (if no skip to Q23 & 24)

23. How did you learn about hospice services?

%	#		
38	5	I know someone who used hospice services	
8	1	I have used hospice services myself	
31	4	I am/was a hospice volunteer	
23	3	I heard from a health care professional	
0	0	I read literature/newspaper/TV/radio/other	media
0	0	I heard from others	
0	0	No response	

24. If you were dying, would you want hospice support?

%	#	
7	1	Yes
50	7	No
43	6	Do not know/ not sure
0	0	No response

### Spiritual Well-Being

25. Do you consider yourself...?

%	#	
17	8	Very religious/ spiritual
58	28	Somewhat religious/ spiritual
8	4	Not very religious/ spiritual
13	6	Not religious/ spiritual
4	2	Do not know
0	0	No response

26. How often do you attend religious or spiritual services?

%	#	
14	6	Always
24	10	Very often
26	11	Sometimes
33	14	Rarely
0	0	Never
2	1	Do not know

27. How often does your religion or spirituality help you face your fears or do what you were afraid to do?

%	#	
31	13	Everyday
19	8	A few times a week
19	8	A few times a month
21	9	Rarely
7	3	Never
2	1	Don't know

### About You

28. How many times in your life have you been seen at an emergency room?

29. How many times in your life have you ever been hospitalized?

29.a. How many nights has \_\_\_\_\_(youth) spent in a hospital in his/her life?

29.b. How many of those nights were psychiatric hospitalizations, for example, for behavior problems or depression?

29.c. How many nights have you spent psychiatrically hospitalized in the past year?

Variable	N	Mean	Std Dev	Min	Max
ER	48	16.3	35.0	0	200
Hospitalized	48	6.6	13.7	0	60
Nights	48	2.4	5.8	0	27
Nights_BP	48	0.1	0.4	0	2
Nights_H_PSY	48	0.6	3.3	0	23

### DURING THE PAST FOUR WEEKS:

30. How many nights has \_\_\_\_\_(youth) stayed in a hospital?

%	#	
94	45	no night spent in the hospital
6	3	1-2 nights spent in the hospital
0	0	3-5 nights
0	0	6-10 nights
0	0	11-20 nights
0	0	>20 nights

31. How healthy do you think \_\_\_\_\_(youth) thinks he/she is feeling right now?

%	#	
31	15	Excellent health
40	19	Very good health
17	8	Good health
13	6	Fair health
0	0	Poor health
0	0	Don't know

32. Is your mother alive?

%	#	
21	10	No
79	38	Yes
0	0	Do not know

33. Your father alive?

%	#	
21	10	No
66	31	Yes
13	6	Do not know