Quality Care at the End of Life Survey

Please rate the following aspects of quality end of life care based on <u>how effective you believe</u> our current care is at the City of Hope. Use your cursor to highlight the number you choose and replace it with an "x".

Structure and Processes of Care

	Strongly Disagree						Strongly Agree
1. The plan of care is based on patient/family goals with consideration of the changing benefits/burden of care.	1	2	3	4	5	6	7
2. Staff have the necessary knowledge and skills required to care for dying patients and their families.	1	2	3	4	5	6	7
3. There is effective continuity of care across settings (ICU, inpatient units, hospice).	1	2	3	4	5	6	7

Physical Aspects of Care

	Strongly Disagree						Strongly Agree
4. Pain is effectively assessed and managed.	1	2	3	4	5	6	7
5. Other symptoms (e.g. dyspnea, agitation) are assessed and managed.	1	2	3	4	5	6	7
6. Consultation is available and effective in managing pain and other symptoms.	1	2	3	4	5	6	7
7. Treatment of pain and symptoms addresses physical, psychological, social and spiritual aspects and incorporates pharmacologic and nonpharmacologic/supportive therapies.	1	2	3	4	5	6	7

Psychological/Psychiatric Aspects of Care

	Strongly Disagree						Strongly Agree
8. Consultation is available and effective by clinical psychology.	1	2	3	4	5	6	7
9. Consultation is available and effective by a psychiatrist.	1	2	3	4	5	6	7
10. Consultation is available and effective by staff (e.g. "Transitions" program) skilled in bereavement.	1	2	3	4	5	6	7
11. Assessment is used to identify people at risk of complicated grief and bereavement.	1	2	3	4	5	6	7
12. Bereavement services are routinely provided to families following the death of a patient.	1	2	3	4	5	6	7

Social Aspects of Care

	Strongly Disagree						Strongly Agree
13. Consultation is available and effective by clinical social work.	1	2	3	4	5	6	7
14. The plan of care reflects important information regarding family relationships.	1	2	3	4	5	6	7
15. Family meetings are conducted in a timely manner to provide information, assist in decision-making, determine wishes and enhance communication.	1	2	3	4	5	6	7
16. Family members are supported through this time of critical illness and death.	1	2	3	4	5	6	7

Spiritual and Existential Aspects of Care

	Strongly Disagree						Strongly Agree
17. Staff are knowledgeable and sensitive to diverse religious/spiritual needs.	1	2	3	4	5	6	7
18. Spiritual assessment is used to identify preferences, rituals, beliefs and concerns.	1	2	3	4	5	6	7
19. Pastoral care/chaplaincy is available and effective.	1	2	3	4	5	6	7

Cultural Aspects of Care

	Strongly Disagree						Strongly Agree
20. Cultural background, concerns and needs of the patient and family are elicited and documented.	1	2	3	4	5	6	7
21. Communication with patients and families is respectful of their cultural preferences regarding disclosure, truth telling and decision making.	1	2	3	4	5	6	7

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Care of the Imminently Dying Patient

	Strongly Disagree					Strongly Agree	
22. The patient's transition to active dying is recognized, documented and communicated appropriately to patient, family and staff.	1	2	3	4	5	6	7
23. Patient/family are offered choices when possible regarding place of death.	1	2	3	4	5	6	7
24. Families are educated regarding signs and symptoms of approaching death.	1	2	3	4	5	6	7
25. Emotional and spiritual support is provided to the patient and family during the dying process and bereavement period.	1	2	3	4	5	6	7
26. Optimum care is provided in the pronouncement of death, procedures for organ/tissue donation, offer of autopsy.	1	2	3	4	5	6	7

Ethical Issues

	Strongly Disagree					Strongly Agree	
27. Patient or surrogate preferences are documented through advance care planning and are honored.	1	2	3	4	5	6	7
28. Ethical concerns are recognized and addressed in a timely way.	1	2	3	4	5	6	7
29. There is appropriate and timely referral to the Ethics Committee.	1	2	3	4	5	6	7
30. Do Not Resuscitate orders are written in a timely way.	1	2	3	4	5	6	7

Other –

31. Overall, please rate the quality of the following:

	Low Quality					High Quality	
a. Your own practice in end of life care.	1	2	3	4	5	6	7
b. Your colleagues practice in end of life care	1	2	3	4	5	6	7
c. The institution's (COH) overall care for dying patients.	1	2	3	4	5	6	7

32. Rate how frequently the following ethical dilemmas occur in your practice setting:

	Uncommon					Very Common	
• Providing honest information vs. destroying hope	1	2	3	4	5	6	7
• Preserving informed patient choices	1	2	3	4	5	6	7
• Patient and family with differing goals	1	2	3	4	5	6	7
• Use of advanced directives	1	2	3	4	5	6	7
• Withholding /withdrawing life sustaining treatments (ventilators)	1	2	3	4	5	6	7
• Withholding/withdrawing food/fluids	1	2	3	4	5	6	7
• Discontinuing life supports	1	2	3	4	5	6	7
• Fear of causing death by giving pain medications	1	2	3	4	5	6	7
• Uncertainty about the patient's prognosis	1	2	3	4	5	6	7
• Providing futile care (care with no hope of success)	1	2	3	4	5	6	7
• Continuing unnecessary lab work or diagnostic procedures	1	2	3	4	5	6	7
• Continuing futile care in fear of lawsuits	1	2	3	4	5	6	7

33. Please rate the following barriers against optimum end of life care.

	Not a Barrier					Severe Barrier	
• Unknown prognosis	1	2	3	4	5	6	7
• Time expenditure needed for dying patients	1	2	3	4	5	6	7
• Staff avoidance of dying patients	1	2	3	4	5	6	7
• Cultural factors influencing End of Life Care	1	2	3	4	5	6	7
• Legal Regulatory restrictions	1	2	3	4	5	6	7
• Other cost considerations	1	2	3	4	5	6	7
• Patient/family reluctance to accept death	1	2	3	4	5	6	7
• Focus on cure/research versus comfort	1	2	3	4	5	6	7
• Palliative care as a core value/mission	1	2	3	4	5	6	7

Quality Care at the End of Life Survey

Please provide the following information about your position at City of Hope:

Profession   **Primary Areas of Your Practice**
                                        (Check all that apply)

__ RN   __ ICU   __ BMT
__ MD   __ Wing 1   __ Pediatrics
__ Social Worker   __ Wing 5   __ Outpatient/Clinic
__ Chaplain   __ Wing 6
__ Other

Please share below any additional comments/thoughts you have about care for patients and families facing death. We would welcome your thoughts about both the strengths and weaknesses of our care: