

Appendix 1 Survey on palliative care support awareness and support needs among hospital physicians and nurses

1. What is your profession?
 - Medical specialist
 - Resident
 - Physician assistant
 - Nurse practitioner
 - Nurse specialist
 - Nurse

2. In which department do you work? (multiple answers allowed)
 - Anesthesiology/Pain Clinic
 - General Internal Medicine/Infectious Diseases/Endocrinology
 - Cardiology
 - Dermatology
 - Emergency Room
 - Gynecology
 - General Surgery
 - Hematology
 - Intensive Care Unit
 - Ear, nose and throat surgery
 - Oral maxillofacial surgery
 - Pediatrics
 - Pulmonology
 - Gastroenterology
 - Nephrology
 - Neurology
 - Neurosurgery
 - Medical Oncology
 - Ophthalmology
 - Orthopedics
 - Clinical Geriatrics
 - Psychiatry
 - Radiation Oncology
 - Rheumatology
 - Rehabilitation Medicine
 - Urology
 - Other

3. Do you mainly work in the outpatient clinic or clinical ward?
 - Clinical ward
 - Outpatient clinic
 - Both

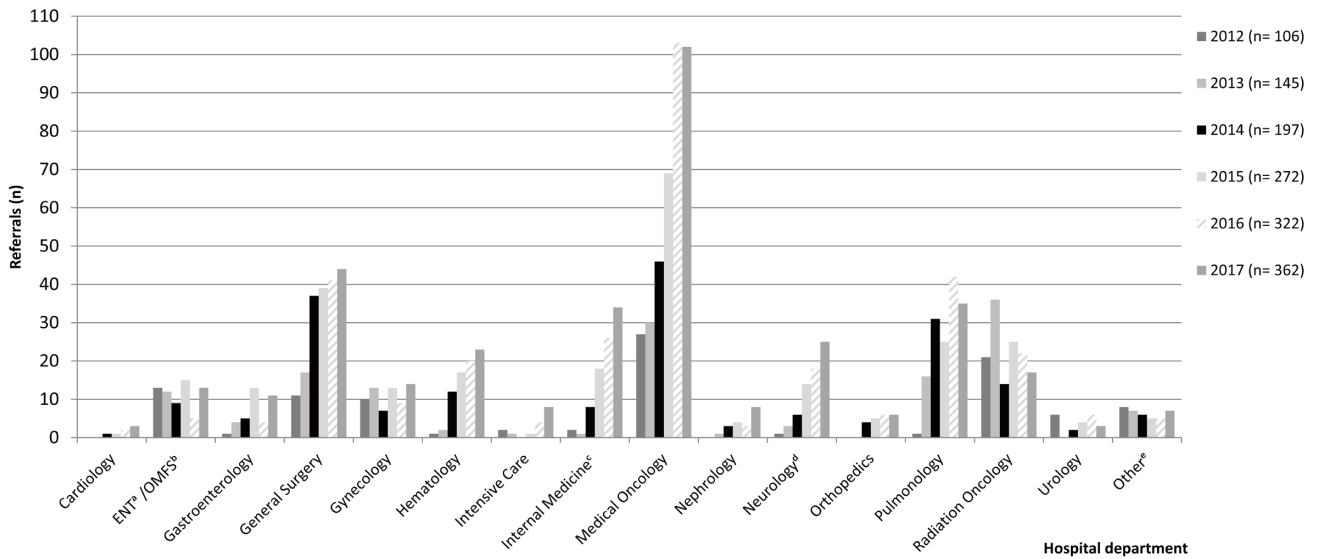
4. Which percentage of your patients is in the palliative care phase?
 - 0–10%
 - 10–30%

- 30–50%
 - >50%
5. In which percentage of your patients would you not be surprised if they would die within 12 months?
- 0–10%
 - 10–30%
 - 30–50%
 - >50%
6. How many of your patients have died in the past year?
- 0–5
 - 6–10
 - 11–15
 - >15
7. From which diseases do your patients with palliative care needs suffer? (multiple answers allowed)
- Cancer
 - Chronic obstructive pulmonary disease
 - Heart failure
 - Neurological disease
 - Other
8. Which three symptoms occur most frequently in your patients with palliative care needs? (maximum of three answers)
- Anxiety
 - Dyspnea
 - Dry mouth
 - Nausea and vomiting
 - Constipation
 - Pain
 - Sleeping problems
 - Lack of appetite
 - Fatigue
 - Confusion/delirium
 - Other
9. Do you use the palliative care guidelines of the National Comprehensive Cancer Organization (NCCN)?
- Yes
 - No
10. Are you familiar with the Leiden University Medical Center (LUMC) palliative care consultation team (PCCT)?
- Yes
 - No
11. How often do you make use of the LUMC PCCT?
- Frequently
 - Often
 - Sometimes

- Rarely
 - Never
12. How would you appraise your experiences with the LUMC PCCT?
- Excellent
 - Good
 - Reasonable
 - Fair
 - Poor
13. Which hospital protocols and tools, developed by the LUMC PCCT, do you know? (multiple answers allowed)
- Management of major bleeding protocol
 - Referral criteria for palliative care consultation
 - Protocol for subcutaneous intravenous catheter
 - Question Prompt List on palliative care
 - Pain protocol
 - Palliative sedation protocol
14. On which topics would you like a protocol, guideline or support?
- Euthanasia
 - Care in the dying phase
 - Decision making and communication about life-sustaining treatment
 - Organizing a memorial service for the family of patients who died at LUMC
 - Other
15. What do you consider a strength of the LUMC PCCT?
16. What do you consider a weakness of the LUMC PCCT?
17. Do you make use of the regional PCCT?
- Yes
 - No, not necessary
 - No, I am not familiar with this PCCT
18. Are department-specific palliative care protocols available within your department?
- Yes
 - No
 - If so, which department-specific protocols?
19. Do palliative care champions work within your department? (multiple answers allowed)
- Yes, one or more physicians
 - Yes, one or more nurses
 - No
20. Does your department have a task force for patients with palliative care needs?
- Yes
 - No
 - If so, can you specify which task force?

21. How often per year is euthanasia performed within your department?
- Never
 - 1 time go to question 23
 - 2–5 times go to question 23
 - >5 times go to question 23
22. Why is euthanasia never performed within your department? (multiple answers allowed)
- No euthanasia requests
 - Insufficient knowledge about the procedure
 - Performing euthanasia is not allowed within the department(s) I work in
 - No support base for performing euthanasia within my team
 - Other
23. Which problems do you experience with the decision-making process and performing of euthanasia? (multiple answers allowed)
- I do not experience problems
 - I have insufficient knowledge
 - Other team members have insufficient knowledge
 - No clear agreement about tasks and responsibilities among treatment team members
 - Patients and/or their families believe they have a ‘right’ to euthanasia
 - Patients and/or their families believe they have a ‘right’ to euthanasia if a euthanasia directive is present (a written declaration of will of the patient regarding euthanasia).
 - Patients and/or their families believe that a proxy may decide when euthanasia can be performed, if the patient is incapacitated.
 - Other
 - Not applicable
24. How often per year is palliative sedation performed within your department?
- Never
 - 1–5 times go to question 26
 - 6–15 times go to question 26
 - >15 times go to question 26
25. Why is palliative sedation never performed within your department? (multiple answers allowed)
- No indications for palliative sedation
 - Insufficient knowledge about the procedure
 - Other
26. Did you use any of the following for the decision-making process and/or performing of palliative sedation? (multiple answers allowed)
- LUMC protocol on palliative sedation
 - Guideline on palliative sedation of the Dutch Comprehensive Cancer Organization (IKNL)
 - Guideline on palliative sedation of the Royal Dutch Medical Association (KNMG)
 - Department-specific protocol on palliative sedation
 - Consultation of the PCCT
 - I did not use any of the above
 - Not applicable

27. Which problems do you experience with the decision-making process and performing of palliative sedation? (multiple answers allowed)
- I do not experience problems
 - I have insufficient knowledge of the guidelines
 - Other team members have insufficient knowledge of the guidelines
 - No clear agreement about tasks and responsibilities of members of the treatment team
 - Patients and their families are informed insufficiently or unclearly
 - Unclear which patients have an indication for palliative sedation
 - Other
 - Not applicable
28. How do you provide aftercare support after the death of a patient? (multiple answers allowed)
- Outpatient appointment
 - Appointment by telephone
 - In writing (condolence letter)
29. Which barriers do you experience regarding the treatment and support of patients with palliative care needs?
30. Which suggestions for improvement do you have regarding the care for patients with palliative care needs and their families?
31. Which suggestions for improvement do you have regarding the care for patients in the dying phase and their families?
32. Which important changes have you observed in the last 5 years regarding palliative care at LUMC?
33. On which topic(s) regarding palliative care would you like education or training?
34. Which other points of attention should be considered by the LUMC PCCT?



^aEar, nose and throat surgery; ^bOral and maxillofacial surgery; ^cGeneral internal medicine, infectious diseases, endocrinology; ^dNeurology, neurosurgery; ^eDepartments without a clinical ward: emergency department, anesthesiology/ pain clinic, dermatology, clinical geriatrics, psychiatry. Also: general practitioners, patients or family members.

Figure S1 Referrals to the PCCT per hospital department (2012–2017). PCCT, palliative care consultation team.

Table S1 Characteristics of respondents to baseline and follow-up surveys on palliative care

Department ^a	2012						2016					
	All (n=291)		Physician (n=52)		Nurse (n=239)		All (n=195)		Physician (n=61)		Nurse (n=134)	
	N	%	N	%	N	%	N	%	N	%	N	%
Cardiology	13	5	0	0	13	5	10	5	1	2	9	7
Gastroenterology	18	6	0	0	18	8	13	7	2	3	11	8
Gynecology	10	3	2	4	8	3	14	7	3	5	11	8
General surgery	26	9	2	4	24	10	25	13	4	7	21	16
Hematology	40	14	5	10	35	15	7	4	2	3	5	4
Intensive care	42	14	6	12	36	15	23	12	6	10	17	13
Internal medicine ^b	29	10	5	10	24	10	18	9	7	11	11	8
ENT ^c /OMFS ^d	9	3	2	4	7	3	5	3	1	2	4	3
Medical oncology	31	11	3	6	28	12	16	8	6	10	10	7
Neurology/neurosurgery	14	5	1	2	13	5	19	10	5	8	14	10
Nephrology	16	6	0	0	16	7	5	3	1	2	4	3
Orthopedics/urology	12	4	3	6	9	4	12	6	2	3	10	7
Pulmonology	14	5	0	0	14	6	9	5	1	2	8	6
Radiation oncology	7	2	7	14	0	0	13	7	11	18	2	1
Other ^e	75	26	18	35	57	24	45	23	11	18	34	25

^a, Exceeds 100% because individual respondents can work within more than one department; ^b, general internal medicine, infectious diseases, endocrinology; ^c, ear, nose and throat surgery; ^d, oral and maxillofacial surgery; ^e, 2012: dermatology, psychiatry, clinical geriatrics, anesthesiology, pediatrics, emergency department, ophthalmology; 2016: dermatology, psychiatry, radiology, clinical geriatrics, anesthesiology, pediatrics, emergency department, rehabilitation medicine, ophthalmology.