

Appendix 1: Electronic Case Report Form ‘patient and care characteristics’

Patient characteristics:

Variable name	Type of variable:	Categories:
Gender	Nominal	<ul style="list-style-type: none"> - Male - Female
Age	Ratio	N/A
Marital status	Nominal	<ul style="list-style-type: none"> - Single, never married - Married or domestic partnership - Widowed - Divorced/Separated
Location of admission	Open, quantified to nominal	N/A
Living situation before admission	Open, quantified to nominal	N/A
Residence before admission	Open, quantified to nominal	N/A
Length of hospice stay	Ratio	N/A

Characteristics of the illness:

Variable:	Type of variable	Categories:
Person initiating admission	Open, quantified to nominal	N/A
Initiating professional for admission	Nominal	<ul style="list-style-type: none"> - General Practitioner - Specialized palliative cancer care nurse - Community nurse

		<ul style="list-style-type: none"> - Medical specialist - Specialist geriatric medicine <p>Otherwise, namely</p>
Elective or acute admission	Nominal	<ul style="list-style-type: none"> - Elective - Acute
Goal of admission	Nominal	<ul style="list-style-type: none"> - Last resort - Respite care - Symptom analysis - Crisis care - Unknown <p>Otherwise, namely</p>
Reasons for admission	Nominal	<ul style="list-style-type: none"> - Physical symptoms and burdens - Psychological: cognitive - Psychological: emotional - Behavioural problems - Social problems - (threatening) overcharge personal caregiver - Spiritual problems - Preferred location of passing - Otherwise, namely
Reason for discharge	Nominal	<ul style="list-style-type: none"> - Deceased - Discharge to home - Transfer/admission to another organization or department - End of support issue
Use of end-of-life care:	Nominal	<ul style="list-style-type: none"> - Palliative sedation during moment of passing - Acute sedation (e.g. massive bleeding or choking) - Euthanasia - Choose consciously to stop eating/drinking

		Other, namely
Patient passed away during admission	Nominal	<ul style="list-style-type: none"> - Yes - No - Unknown
Preferred location of passing during admission	Nominal	<ul style="list-style-type: none"> - Home - Hospice - Hospital - Nursing home - Elderly home - At family/friends - Patients and/or closest ones are unable to speak about this - Unknown - Other, namely
Changed preferred location of passing	Nominal	<ul style="list-style-type: none"> - Yes - No - Unknown
Main diagnoses	Open, quantified to nominal	N/A
Location primary tumour	Nominal	<ul style="list-style-type: none"> - Digestive system - Respiration intrathoracally - Female genitals - Mamma - Kidneys and urinary tract - Hematology - Male genitals - Skin - Brain/central nervous system - Unknown

		<ul style="list-style-type: none"> - Other, namely
Metastases found?	Nominal	<ul style="list-style-type: none"> - No, no metastases - Liver - Lungs - Pleura - Bone - Peritoneum - Skin - Meninges - Brain - Adrenal - Lymph nodes - Other, namely
Physiscal dimension:		
Case of organ failure	Open, quantified to nominal	N/A
Neurological problems	Open, quantified to nominal	N/A
Other physical problems	Open, quantified to nominal	N/A
Co-morbiditiesmorbidityies	Nominal	<ul style="list-style-type: none"> - Other malignity - Lung disease - Heart and vascular disease - Gastrointestinal tract - Urinary tract and reproductive organs - Muscles, connective tissue and joints - Central and peripheral nervous system

		<ul style="list-style-type: none"> - Metabolism and clotting disorders - Infectious diseases
Psychological dimension:		
Orientation in person, place and time	Nominal	<ul style="list-style-type: none"> - Yes - No - Unknown
Memory problems	Nominal	<ul style="list-style-type: none"> - Yes <ul style="list-style-type: none"> • Short term memory • Long term memory • Unknown • Other, namely No
Social dimension:		
Patients worries about influence of illness on closest ones	Open, quantified to nominal	
Experienced support by closest ones	Nominal	<ul style="list-style-type: none"> - Yes - No - Unknown
Spiritual dimension:		
Support from religion	Nominal	<ul style="list-style-type: none"> - Yes <ul style="list-style-type: none"> • Catholic • Reformed (in Dutch: Hervormd) • Reformed (in Dutch: Gereformeerd) • Protestant • Islam • Jewish • Hindu • Buddhist

		<ul style="list-style-type: none"> • Humanistic • Other, namely <p>- No</p>
Other information:		
Number of days from admission until markedmarked palliative phase	Ratio	N/A
Transition to palliative phase is discussed with patient	Nominal	<ul style="list-style-type: none"> - Yes - No - Unknown
Life expectancy at admittance	Open, quantified to nominal	N/A
Stage of illness at admission	Nominal	<ul style="list-style-type: none"> - Mainly disease-targetedpalliation - Mainly symptom-targeted- palliation - Terminal palliation - Doubting - Unknown
Which disease-targeted therapy has been deployed in the past three months?	Open, quantified to nominal	N/A
Problems during admission that had an influence on the care process (Multiple answers possible)	Nominal	<ul style="list-style-type: none"> - Infection - Bleeding - Anaemia - Oedema - Bronchopulmonary insufficiency - Pleural fluid - Ascites - Sub ileus/ passing problems - Urine retention

		<ul style="list-style-type: none"> - Renal insufficiency - Icterus - Stomatitis - Cachexia - Pressure ulcers - Wound - Reduced awareness - Delirium - Coping - Lack of social contacts - Extreme suffering - Other, namely
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Experienced symptoms:

Experienced symptoms were operationalized with the four-dimensional Utrecht Symptom Diary (USD-4D).

Indication for and deploying of (non-)pharmacological interventions:

Deployed (non-)pharmacological interventions were collected as an open variable. This variable was later categorised and quantified as nominal. Indications of interventions were collected as open.

Assessment tools used:

AssessmentA tools used were collected as an open variable. This variable was later categorized and quantified as nominal.

Appendix 2: Description of patient and illness characteristics.

Information about	N (%)	Information about	N (%)
<u>Patient characteristics</u>		<u>Continuation illness characteristics</u>	
Gender		~ problems during admission	
Male	44 (42)	Existential suffering	11 (11)
Age (years)	73 (15..4)*	Urine retention	11 (11)
Marital status		Infection	8 (8)
Married/registered partnership	43 (41)	Bleeding	5 (5)
Widowed	21 (30)	Wounds	3 (3)
Single, never married	17 (16)	Coping	3 (3)
Divorced	12 (12)	Anemia	3 (3)
Living situation before admission		Cachexia	2 (2)
Single	47 (45)	Lack of social contacts	2 (2)
Living together	32 (31)	Ascites	2 (2)
Living in Institution	5 (5)	Pleural fluid	1 (1)
Missing	20 (19)	Other	34 (33)
Residence before admission			
Home	38 (37)	Admission	
Hospital	53 (51)	Initiating person	
Nursing/elderly home	8 (8)	Patient/family	53 (51)
Living at family	2 (2)	Missing	30 (29)
Missing	3 (4..2)	Initiating professional	
Length of hospice stay (days)	20		
	(47..5)**	General practitioner	13 (13)
		Medical specialist	8 (8)
		District Nurse	1 (1)
		Specialist elderly care	1 (1)
		Missing	67 (64)
		Other	14 (14)
		Goal of admission	
<u>Illness characteristics</u>			
Illness			
Main diagnoses			
Cancer - Location primary tumor			
Digestive system	25 (24)		

Respiration intrathoracally	24 (23)	Last resort	100 (96)
Kidneys and urinary tract	6 (6)	Respite care	2 (2)
Female genitals	6 (6)	Crisis care	1 (1)
Brain/central nervous system	6 (6)	Unknown	2 (2)
Mamma	5 (5)	Other	1 (1)
Unknown/Space-occupying lesion	3 (3)	Reasons for admission	
Hematology	2 (2)	Physical symptoms and burdens	82 (79)
Male genitals	2 (2)	Preferred location of passing	17 (16)
Mouth	2 (2)	Social problems	16 (15)
		(Threatening) overcharge personal caregiver	14 (14)
Skin	1 (1)	Psychological: cognitive	11 (11)
Organ failure		Psychological: emotional	3 (3)
Heart failure	8 (8)	Spiritual problems	2 (2)
Lung failure	2 (2)	Other	14 (14)
Neurological problems		Transition to palliative phase	
ALS	1 (1)	Date transition to palliative phase in days	27 (157)**
CVA	1 (1)	Discussed transition to palliative phase	65 (63)
Other physical problems***	10 (10)	Life expectancy	
Cancer - Metastases		< 3 months	66 (64)
No metastases	37 (36)	< 1 month	6 (6)
Liver	24 (23)	≥ 3 months	5 (5)
Lungs	21 (20)	< 1 week	4 (4)
Bone	20 (19)	Unknown	23 (22)
Lymph nodes	15 (14)	Stage of the illness	
Brain	9 (9)	Mainly symptom-targeted palliation	89 (86)
Peritoneum	7 (7)	Terminal palliation	8 (8)
Adrenal	5 (5)	Unknown	4 (4)
Pleura	5 (5)	Mainly disease-targeted palliation	2 (2)
Skin	3 (3)	Doubting	1 (1)
Meninges	1 (1)		

Other	11 (11)	Disease-targeted therapy	
Actual co-morbidity's		Chemotherapy	13 (13)
Heart and vascular disease	50 (48)	Medicamental	12 (12)
Metabolism and clotting disorders	29 (28)	Radiotherapy	9 (9)
Lung disease	18 (17)	Surgery	4 (4)
Urinary tract and reproductive organs	18 (17)	Immunotherapy	1 (1)
Muscles, connective tissue and joints	12 (12)	Other	4 (4)
Central/peripheral nervous system	10 (10)		
Other malignity	8 (8)	Dying	
Gastrointestinal tract	5 (5)	Reasons dismissal	
Infection diseases	2 (2)	Passed away	103 (99)
None	11 (11)	Use of end-of-life-care	
		Palliative sedation (structural use of a	
Other	32 (31)	sedative)	52 (50)
		Euthanasia	5 (5)
Multidimensionality		Acute sedation	1 (1)
Orientation in time, place, person	57 (55)	Missing	8 (8)
Memory problems	25 (24)	Other	37 (36)
Support from closest ones	44 (42)	Preferred location of dying	
Support religion	38 (37)	Hospice	65 (63)
Patient worries	14 (14)	Home	2 (2)
Problems during admission		Unspeakable for patient/closest ones	2 (2)
Delirium	30 (29)	Unknown	35 (34)
Pressure ulcers	24 (23)	Changed preferred location of dying	
Edema	19 (18)	No	20 (19)
Sub ileus/passing problems	16 (15)	Yes	2 (2)
Reduced awareness	16 (15)	Missing	3 (3)
Bronchopulmonary insufficiency	16 (15)	Unknown	79 (76)

Percentages are rounded and therefore may not add up to 100.

* Mean (SD) ** Median (IQR), due to not normal distribution ***As primary problem.

