Supplementary material

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Supplementary material 1. Protocol



PROSPERO

International prospective register of systematic reviews

Systematic Review of Outcomes Relevant to the Last Days of Life to Inform the Development of a Core Outcome Set for Best Care for the Dying

To enable PROSPERO to focus on COVID-19 submissions, this registration record has undergone basic automated checks for eligibility and is published exactly as submitted. PROSPERO has never provided peer review, and usual checking by the PROSPERO team does not endorse content. Therefore, automatically published records should be treated as any other PROSPERO registration. Further detail is provided here.

Citation

Sofia Zambrano Ramos, Martina Egloff, Nora Luethi, Steffen Eychmüller. Systematic Review of Outcomes Relevant to the Last Days of Life to Inform the Development of a Core Outcome Set for Best Care for the Dying. PROSPERO 2020 CRD42020155875 Available from: https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42020155875

Review question

In this systematic review we aim to identify and summarize:

- What outcomes are systematically measured at the end of life?
- How are outcomes currently assessed? that is, through which specific tools.
- When are they assessed?
- Who reports on the outcome: the patient, the family or the health professionals?
- Which other outcomes have been identified in the literature in terms of 'goals of care', 'satisfaction with care', 'quality of life', 'quality of end of life', 'quality of death and dying', 'perceptions', 'standards', 'end of life wishes', or 'factors considered important in the last days of life' from the patient or family perspective?

Searches

Publications will be retrieved without a date limit from the following electronic databases: MEDLINE, CINAHL, PsycINFO, and Embase. Unpublished interventional studies will be identified from the International Clinical Trials Registry Platform (ICTRP) and the Cochrane Central Register of Controlled Trials (CENTRAL). In addition, a manual search of references from relevant articles will lead to identifying other potentially important publications. National guidelines, statements or standards will be searched for on the Internet and through a snowballing technique via the members of the Collaboration for Best Care for the Dying Person.

Language will not be filtered prior to study selection. Studies in English, Spanish, and German will be considered for inclusion in the review. Once all terms are defined and the search has been piloted, the search terms will be adapted to the syntax of all databases.

Types of study to be included

The review will focus on outcomes employed in interventional studies, as well as in other peer-reviewed literature, including observational studies, surveys, and qualitative studies. Grey literature will be included when relevant. Outcomes

Page: 1 / 6



from ongoing trials registered in the International Trials Registry Platform (ICTRP) will be extracted.

The review will include randomized controlled trials, non-randomized controlled trials, quasi-experimental, before and after studies, prospective studies, and cohort studies. Qualitative and survey studies which focus on outcomes, quality of life, or on family and patient preferences for the last days of life will also be included.

We will exclude:

- Studies reporting on end of life aspects within paediatrics, on non-human research, or from the perspective of healthy individuals/general population, with the exception of bereaved family members and health professionals.
- Studies reporting beyond the last month of life.
- Letters, editorials, book chapters, and case studies.

Condition or domain being studied

The systematic review aims to identify outcomes which are considered important during the last days of life from the perspective of patients, family members, clinicians, and researchers. The outcomes can be identified in the context of any chronic illness or condition which is at an advanced stage such as advanced cancer, end-stage kidney, lung or heart disease, dementia, etc., and taking into account the variety of contexts where dying people can be cared for at the end of life (e.g. home, hospital, hospice, aged care facilities).

Participants/population

This review will consider studies if they include adults who were at the end of life. Since the term has a broad definition of a life expectancy of months to days of life, we will narrow our selection to include only those studies reporting no longer than the last month of life. Non-interventional studies will be considered if outcomes are defined or reported by patients, health professionals, and/or caregivers. Outcomes will be included whether they directly affected the patient, the caregiver, the health professionals, or the health system as a whole. Studies undertaken in any setting of care (hospital, hospice, community, home) will be included.

Intervention(s), exposure(s)

No particular intervention or exposure will be the focus of this review.

Comparator(s)/control

N/A

Context

For the purpose of the systematic review, we need to predefine two central concepts: outcomes, and end of life. Considering the specific features and domains of palliative care, outcomes will be understood as the effect or the end result of a given treatment/intervention on the patient, the family of the patient, the medical services, or on the health system. Although the COS will focus on patient and family outcomes, the review will take into account all other outcomes collected in interventional studies. Outcomes to be extracted from the studies will include not only those strictly denoted as 'outcomes' or 'endpoints', but particularly in the non-interventional studies, they will be identified in terms of specific areas of interest such as: 'satisfaction with care', 'quality indicators; e.g. 'quality of life', 'quality of end of life', 'quality of death and dying', 'perceptions', 'standards', 'goals of care', 'end of life wishes', or 'factors considered important in the last days of life'.

In order to access a broad selection of literature, our scope will consider end of life taking into account the lack of a standard definition or a specific time frame for the term and will thus include literature focused on people with



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In order to access a broad selection of literature, our scope will consider end of life taking into account the lack of a standard definition or a specific time frame for the term and will thus include literature focused on people with



incurable, advanced illnesses with a life expectancy of one month to days of life.

Main outcome(s)

The review aims to identify existing outcomes of care for the last days of life

Measures of effect

N/A

Additional outcome(s)

N/A

Measures of effect

N/A

Data extraction (selection and coding)

Initially, two review team members will screen the first 100 titles and abstracts independently and will compare their results. After checking for disagreements, titles and abstracts of all articles identified through the searches will be screened by independently by two of the researchers who will be blinded to each other's decisions. In this initial screening process, duplicates will be discarded and each study will be categorized as: a) to be included, b) to be discarded, or c) unsure. Full-texts of all potentially relevant articles, which fell in the 'to be included' or the 'unsure' categories, will be obtained and will be assessed according to the inclusion criteria. The process of article selection will be shown in a PRISMA flow diagram and the review will adhere to the PRISMA reporting guidelines. At all stages, disagreements will be resolved through discussions until consensus is reached, a third reviewer will be involved if there is no agreement between the first two reviewers.

From each included study a minimum of information will be extracted through a data extraction tool. The tool will be piloted and refined with an initial set of articles.

Risk of bias (quality) assessment

Since the main goal of the systematic review is to aid in the generation of the initial list of outcomes, the risk of bias of each of the studies, as well as the quality of each of the studies will not be assessed.

Strategy for data synthesis

A narrative synthesis of the findings of the review will be structured around the types of outcomes measured, the tools employed to measure these outcomes, the characteristics of the target population, and type of intervention (if it is an interventional study).

Analysis of subgroups or subsets

If enough data are available, a subgroup narrative synthesis of differences between outcomes employed in studies of cancer and non-cancer patients, within non-malignant illnesses, differences according to age groups, place of care, and place of death will be made.

Contact details for further information



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Organisational affiliation of the review

University Centre for Palliative Care, Inselspital

Review team members and their organisational affiliations

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Professor Steffen Eychmüller. University Centre for Palliative Care, Inselspital, Bern University Hospital, Bern, Switzerland

Collaborators

Dr Susanna Dodd. Department of Biostatistics, Institute of Translational Medicine, University of Liverpool

Type and method of review

Systematic review

Anticipated or actual start date

02 September 2019

Anticipated completion date

31 May 2020

Funding sources/sponsors

This systematic review is being performed in the context of COS Development within a project called 'iLIVE'. iLIVE is

a project funded by the European Union's Horizon 2020 Research and Innovation Programme under Grant agreement no: 825731. The dissemination activities within the iLIVE project do not represent the opinion of the European Community and only reflect the opinion of the authors and/or the Consortium.
Conflicts of interest
Language
English
Country
Switzerland





Stage of review

Review Ongoing

Subject index terms status

Subject indexing assigned by CRD

Subject index terms

Delphi Technique; Endpoint Determination; Humans; Outcome Assessment, Health Care; Terminal Care

Date of registration in PROSPERO

28 April 2020

Date of first submission

02 December 2019

Details of any existing review of the same topic by the same authors

N/A

Stage of review at time of this submission

Stage	Started	Completed
Preliminary searches	Yes	Yes
Piloting of the study selection process	Yes	Yes
Formal screening of search results against eligibility criteria	Yes	No
Data extraction	No	No
Risk of bias (quality) assessment	No	No
Data analysis	No	No

The record owner confirms that the information they have supplied for this submission is accurate and complete and they understand that deliberate provision of inaccurate information or omission of data may be construed as scientific misconduct.

The record owner confirms that they will update the status of the review when it is completed and will add publication details in due course.

Versions

28 April 2020

Supplementary material 2.Deviations from the protocol

Protocol	Adjustment	Reason
"We aim to identify and	We did not extract the tools for	This was not feasible due to
summarize how outcomes are	each of the outcomes	the large number of studies to
currently assessed, that is,		review (n=619)
through which specific tools."		
"We will include studies in	We included studies in English	We had initially considered
English, Spanish, and German."		including all three languages as
		our team of reviewers
		included people who speak at
		least two of the languages.
		However, as not all of them
		speak all three languages, a
		comparison of the screening
		results would not have been
		possible.
"Grey literature will be	We included only white literature	We had initially wanted to add
included when relevant."		outcomes from grey literature.
		However since we would be
		gathering data in other study
		phases other perspectives, we
		decided to only include
		published research studies.
Outcomes from ongoing trials	We included only published	The level of detail of the
will be extracted.	studies	database was not good
		enough to extract the
		information we required for
		each of the outcomes.
		Therefore to reduce missing
		data, we decided to not
		include outcomes from
		ongoing studies.

Supplementary material 3. Search strategy

Primary Search Embase (Elsevier)

No. Query

Results 2,498 Date 24 Feb 2022

#1 (('terminal care'/exp OR bereave* OR hospice*:de,it,lnk,ab,ti OR 'advanced cancer':ab,ti OR 'end of life' OR 'terminally ill':de,it,lnk,ab,ti OR palliative*:ab,ti OR 'palliative therapy'/exp) AND (((last OR final) NEAR/4 (hour* OR day* OR minute* OR stage* OR week* OR month* OR moment*)):ab,ti,kw) OR (((week* OR day*) NEXT/1 (before OR 'time of') NEXT/1 (death OR dying)):ab,ti,kw) OR (((shutdown OR deteriorat* OR 'shut* down') NEAR/2 body):ab,ti,kw) OR deathbed:ab,ti,kw OR 'time of death'/exp) AND ('quality of life assessment'/de OR 'health care quality'/de OR 'patient satisfaction'/de OR 'patient preference'/de OR 'needs assessment'/de OR ((quality NEAR/2 (care OR life)):ab,ti,kw) OR (((wish* OR prefere* OR perception* OR need* OR want* OR satisfaction) NEAR/1 patient*):ab,ti,kw) OR 'outcome assessment'/de OR 'treatment outcome'/de OR outcome*:ab,ti,kw OR 'end point*':ab,ti,kw OR endpoint*:ab,ti,kw) NOT ([animals]/lim NOT [humans]/lim) NOT ([conference abstract]/lim OR [letter]/lim OR [note]/lim OR [editorial]/lim) NOT (([newborn]/lim OR [infant]/lim OR [child]/lim)

Translations

Ovid MEDLINE(R) ALL

1 ((((exp Terminal Care/ or bereave\$.af. or hospice\$.mp. or advanced cancer.tw. or end of life.af. or terminally ill.mp. or palliative\$.tw. or Palliative Care/) and ((last or final) adj4 (hour* or day* or minute* or stage* or week* or month* or moment*)).ab,ti,kw.) or ((week* or day*) adj1 (before or "time of") adj1 (death or dying)).ab,ti,kw. or ((shutdown or deterio rat* or "shut* down") adj2 body).ab,ti,kw. or deathbed.ab,ti,kw.) and ("Quality of Health Care"/ or exp Patient Satisfaction/ or Needs Assessment/ or (quality adj2 (care or life)).ti,ab,kw. or ((wish* or prefere* or perception* or need* or want* or satisfaction) adj1 patient*).ab,ti,kw. or Outcome Assessment, Health Care/ or "Outcome and Process Assessment, Health Care"/ or treatment outcome/ or outcome*.ab,ti,kw. or "end point*".ab,ti,kw. or endpoint*.ab,ti,kw.)) not (exp animals/ not humans.sh.) not (comment/ or editorial/ or letter/ or exp Congresses as Topic/) not ((exp infant/ or exp child/ or adolescent/) not Adult/) 1821

APA PsycInfo

(exp palliative care/ or hospice/ or terminal care.mp. or bereave\$.af. or hospice\$.mp. or advanced cancer.tw. or end of life.af. or terminally ill.mp. or palliative\$.tw.) and (((last or final) adj4 (hour* or day* or minute* or stage* or week* or month* or moment*)) or ((week* or day*) adj1 (before or "time of") adj1 (death or dying)) or ((shutdown or deteriorat* or "shut* down") adj2 body) or deathbed).ab,ti,id. and ("quality of life measures"/ or "quality of care"/ or client satisfaction/ or needs assessment/ or (quality adj2 (care or life)).ab,ti,id. or ((wish* or prefere* or perception* or need* or want* or satisfaction) adj1 patient*).ab,ti,id. or "treatment process and outcome measures"/ or treatment outcomes/ or outcome*.ab,ti,id. or "end point*".ab,ti,id. or endpoint*.ab,ti,id.) 566

CINAHL (Ebsco)

Query Search modes - Boolean/Phrase Results 145

S1 (MH "Terminal Care+" OR bereave* OR hospice* OR "advanced cancer" OR "end of life" OR "terminally ill" OR palliative*) AND (((week* OR day*) N1 (before OR "time of") N1 (death OR dying)) OR ((shutdown OR deteriorat* OR "shut* down") N2 body) OR deathbed) AND (MH "Quality Patient Care Scale" OR MH "Quality of Health Care" OR MH "Patient Satisfaction+" OR MH "Needs Assessment" OR (quality N2 (care OR life) OR (wish* OR prefere* OR perception* OR need* OR want* OR satisfaction) N1 patient*) OR MH "Outcome Assessment" OR MH "Outcomes (Health Care)" OR MH "Treatment Outcomes" OR outcome* OR "end point*" OR endpoint*)

Supplementary material 4. Complete list of outcomes

Rank	Outcome	Times assessed	%	COMET category			
Kank	Outcome	assessed	70	Life Resource			Adverse
				Physiological	impact	use	event
1	Chemotherapy use	169	8.7%			Х	
2	Hospital admission	151	7.7%			x	
3	Place of death	140	7.2%		Х		
4	ICU admission	132	6.8%			x	
5	ER visit	125	6.4%			x	
6	Ventilation use	55	2.8%			x	
7	Hospitalization length	51	2.6%			x	
8	CPR	49	2.5%			x	
9	Pain	47	2.4%	x			
10	Quality of care	41	2.1%		Х		
11	Dyspnea	36	1.8%	x			
12	Artificial nutrition	34	1.7%			x	
13	Radiotherapy use	32	1.6%			x	
14	Late hospice enrollment	31	1.6%			x	
15	Quality of life	30	1.5%		Х		
16	Nausea or vomiting	27	1.4%	х			
17	Hospice utilization	27	1.4%			x	
18	Anxiety	25	1.3%	х			
19	Non-further described symptoms	21	1.1%	х			
20	Depression	20	1.0%	х			
21	Functional status	19	1.0%		Х		
22	Symptomsmanagement	15	0.8%			x	
23	Care setting transitions	14	0.7%			x	
24	Blood transfusion	14	0.7%			x	
25	Antibiotic use	14	0.7%			x	
26	Quality of dying	13	0.7%		X		
	Non-further described anticancer						
27	treatment	13	0.7%			х	
28	Comfort	13	0.7%		Х		
29	Palliative care use	13	0.7%			X	
30	Appetite-related issues	13	0.7%	X			
31	Immunotherapy	13	0.7%			X	
32	Dialysis	11	0.6%			х	
33	DNR order Non-further described	11	0.6%		X		
34	medications	11	0.6%			x	
35	Satisfaction with care	10	0.5%		Х		
36	Surgical interventions	10	0.5%			x	
0.7	Death at preferred place of	4.0	0.50/				
37	death	10	0.5%		Х		
38	Drowsiness	9	0.5%	X			
39	Tiredness	9	0.5%	X			
40	Targeted oral therapy	9	0.5%			X	
41	Wellbeing	9	0.5%		Х		
42	Pain management	8	0.4%			X	
43	Confusion	8	0.4%		Х		
44	Dysphagia EOL discussions with patient or	9	0.5%	Х			
45	family	8	0.4%		х		
46	Physician visits	8	0.4%			x	
47	Diagnostic tests	7	0.4%	x			
48	Nutrition and hydration	7	0.4%			х	

49	Contact with GP	7	0.4%			х
50	Imaging	7	0.4%	Х		
51	Opioids use	7	0.4%			х
52	Number of prescription drugs	7	0.4%			х
53	Treatment goal	7	0.4%		х	
54	Sedation	7	0.4%			х
55	Appropriateness of medication	7	0.4%		х	
56	Place of care	6	0.3%			х
57	Sleepingissues	6	0.3%	x		
58	Contact with home-care services	6	0.3%			x
59	Fever	6	0.3%	X		
60	Constipation	6	0.3%	x		
61	ICU length	5	0.3%			Х
62	Concordance of care with preferences	5	0.3%		x	
63	Hormonal therapy	5	0.3%		^	х
64	Time at home	5	0.3%		x	^
65	Aggressive /High-intensity care	5	0.3%		^	х
66	Renal replacement therapy	4	0.2%			x
67	Cough	4	0.2%	Х		^
68	Fatigue	4	0.2%	X		
69	Delirium	4	0.2%	x		
70	Myoclonus	4	0.2%	x		
71	Bladderproblems	4	0.2%	x		
72	Analgesicuse	4	0.2%	^		х
73	Diarrhea	4	0.2%	x		^
. 0	Late referral or access to	•	0.270	^		
74	palliative care	4	0.2%			Х
75	Care preferences/wishes	3	0.2%		Х	
76	Dignity and respect	3	0.2%		Х	
77	Family present at death Hospitalization length with	3	0.2%		Х	
78	palliative care	3	0.2%			х
79	Agitation	3	0.2%	x		
80	Contact with health services	3	0.2%			х
81	Pressure injuries	3	0.2%	x		
82	Bowel problems	3	0.2%	x		
83	Seizures	3	0.2%	x		
84	Mental status	3	0.2%		Х	
85	Suffering	3	0.2%		Х	
86	Dry mouth	3	0.2%	X		
87	Terminal phase recognition	3	0.2%		Х	
88	Palliative care referral	3	0.2%		Х	
89	Physical restraint	3	0.2%		Х	
90	Unmet needs	3	0.2%		Х	
91	Life sustaining treatment	3	0.2%			х
92	Urinary catheterization	3	0.2%			x
93	Rattle	2	0.1%	x		
94	Percutaneousprocedures	2	0.1%			Х
95	Symptomsburden	2	0.1%	X		
96	Endoscopy	2	0.1%	X		
97	Physical therapy	2	0.1%			х
98	Family awareness of dying	2	0.1%		X	
99	Appointment of a health care proxy	2	0.1%		х	
100	Death preparedness	2	0.1%		X	
101	Antidepressant use	2	0.1%		= =	х
	,	_				

400	Discolar and Con-	0	0.40/			
102	Blood sampling	2	0.1%	Х		
103	Psychological distress	2	0.1%		X	
104	Decision-making capacity	2	0.1%		X	
105	Prognostic awareness	2	0.1%		X	
106	Advance directive	2	0.1%		X	
107	Speech therapy	2	0.1%			Х
108	Caregiver's depression	2	0.1%			Х
109	Sweating	2	0.1%	Х		
110	Intravenoustreatment	2	0.1%			Х
111	Treatments received	2	0.1%			Х
112	Invasive procedures	2	0.1%			Х
113	Palliative radiotherapy	2	0.1%			Х
114	Decision-making process	2	0.1%		X	
115	Personal cleanliness	2	0.1%		x	
116	Muscle weakness	2	0.1%	X		
117	Documentation of ACP	2	0.1%		x	
118	Vasopressors	2	0.1%			х
119	Advanced diagnostic examinations	2	0.1%	Х		
120	Visits from the hospice staff	2	0.1%	^		х
120	Pulmonary artery pressure	2	0.170			^
121	monitoring	2	0.1%	x		
122	Non-pharmacological strategies	2	0.1%		x	
123	Skin problems	2	0.1%	x		
124	Nursing care	2	0.1%			Х
125	Spiritual wellbeing	2	0.1%		x	
126	Oxygen	2	0.1%			х
127	Swallowing problems	2	0.1%	x		
128	Caregiver-staff communication	2	0.1%			х
129	Swelling	2	0.1%	x		
130	Central line	2	0.1%			х
131	Therapeutic procedures	2	0.1%			х
132	Palliative care drugs	2	0.1%			х
133	Palliative care needs	2	0.1%			х
134	Occupational therapy	2	0.1%			х
135	Hemorrhage	1	0.1%	x		
136	Access to a care coordinator	1	0.1%		x	
137	Satisfaction with physician	1	0.1%		x	
138	Caregiver's distress	1	0.1%		,	х
139	Chest pain	1	0.1%	Х		^
140	Inotropes use	1	0.1%	^		х
141	Resilience	1	0.1%		Х	^
142	Interdisciplinary collaboration	1	0.1%		Α	х
143	Specialty consultations	1	0.1%			X
144	Endoscopic procedure	1	0.1%			X
145	Emotional support	1	0.1%		Х	^
146	Edema	1	0.1%	Х	^	
140	Being able to provide a self-	'	0.170	^		
147	report of pain intensity	1	0.1%		x	
148	Late care setting transitions	1	0.1%			Х
149	Communication with family	1	0.1%		x	
150	Caregiver's experience of the	4	0.49/			
150	dying phase Respiratory tract secretions	1	0.1%			Х
151	management	1	0.1%			х
152	Care for imminent death	1	0.1%		x	
153	Sharing concerns with loved ones	1	0.1%		Х	
100	01100	'	0.170		^	

154	Laxative use in opioids Stent/nephrostomy tube	1	0.1%			X	
155	placement	1	0.1%			х	
156	Distress	1	0.1%		Х		
157	Withdrawal of life-prolonging or life-sustaining treatments	1	0.1%		x		
158	Life-extending procedures	1	0.1%			x	
159	Cardiac device implantation	1	0.1%			x	
160	Memory or thinking problem	1	0.1%		x		
161	Hematuria	1	0.1%	x			
162	Distress from fatigue	1	0.1%		x		
163	Psychosocial interventions	1	0.1%			x	
164	Mood	1	0.1%		x		
165	Cold or influenza symptoms	1	0.1%	X			
166	Most bothersome symptom Relief of strain and negative	1	0.1%	Х			
167	emotions in caregivers	1	0.1%		X		
168	Epistaxis	1	0.1%	X			
169	Respiratory symptoms	1	0.1%	X			
170	Musculoskeletal pain	1	0.1%	X			
171	Sadness	1	0.1%		x		
172	Dizziness or unsteadiness	1	0.1%	x			
173	Drugs omission Caregiver's need for more	1	0.1%		x		
174	information	1	0.1%			x	
175	Delirium management	1	0.1%			x	
176	Urinalysis	1	0.1%	x			
177	Spiritual support	1	0.1%		x		
178	Vaginal bleeding	1	0.1%	x			
179	Suggestions to improve care	1	0.1%		x		
180	Admission to general ward	1	0.1%			x	
181	ICD management	1	0.1%		x		
182	Visits from nurse practitioners	1	0.1%			x	
183	Dying without symptoms	1	0.1%		x		
184	Falls	1	0.1%	x			
185	Timing of EOL discussions	1	0.1%		x		
186	Weightloss	1	0.1%	x			
187	Dyspnea management	1	0.1%			x	
188	Cystourethroscopy	1	0.1%	x			
189	Chronic control disease medication	1	0.1%			x	
	Caregiver's need for more support for practical running of						
190	household	1	0.1%			x	
191	Pooreyesight	1	0.1%	x			
	Effects of defibrillator shocks on						
192	family	1	0.1%				Х
193	Hemodynamic support Caregiver's need for more	1	0.1%			Х	
194	support for transport	1	0.1%			X	
195 196	Psychosocial status Number of unique physicians	1	0.1% 0.1%		X	V	
196	providing care	1	0.1%			Х	v
197	Clinical complications Family involvement		0.1%		v		х
	Family involvement	1			Х	v	
199	Anxiolytic use Caregiver's need for more	1	0.1%			Х	
200	support looking after patient	1	0.1%			Х	
201	Ambulance use	1	0.1%			Х	
202	Dysuria	1	0.1%	x			
203	Drugsinteractions	1	0.1%				х

204	Caregivers' quality of life	1	0.1%			Х	
205	Respiratory secretions	1	0.1%	Х		*	
206	Family preparedness for death	1	0.1%	^	Х		
207	Respiratory therapy	1	0.1%		^	Х	
208	Family presence in hospital	1	0.1%		х	^	
209	Restlessness	1	0.1%	x	Α		
203	Effects of defibrillator shocks on	'	0.176	^			
210	patient	1	0.1%				Х
211	Community-based care	1	0.1%			х	
212	Pain prescription access	1	0.1%		Х		
213	Concentration	1	0.1%		Х		
214	Palliative chemotherapy	1	0.1%			X	
215	Self-perceived burden to others	1	0.1%		Х		
216	Bleeding	1	0.1%	x			
217	Hospice length	1	0.1%			x	
218	Electrocardiography	1	0.1%	x			
219	Soiled bedding or clothing	1	0.1%		х		
220	Freedom for relatives when visiting	1	0.1%		х		
221	Caregiver's anxiety	1	0.1%		^	Х	
222	Acute care episodes	1	0.1%			X	
223	Admission to geriatric ward	1	0.1%				
223	Care provision	1	0.1%		v	Х	
225	Dying with unrelieved pain	1	0.1%		X		
225	Pastoral care	1	0.1%		X		
220	Hospital admission with	,	0.176		Х		
227	palliative care involvement	1	0.1%			x	
228	Patient - doctor communication	1	0.1%		Х		
229	Emotionalassessment	1	0.1%		Х		
230	Patient awareness of dying	1	0.1%		Х		
231	Symptom documentation	1	0.1%		Х		
232	Patient-staff communication	1	0.1%		Х		
233	Appropriateness of care	1	0.1%		Х		
234	Peace	1	0.1%		Х		
235	Cardiac catheterization	1	0.1%			x	
236	Gastrointestinalbleeding	1	0.1%	x			
237	Dysphagia	4	0.1%	*			
238	GCSF injection	1	0.1%			x	
239	Agitation management	1	0.1%			x	
240	General condition	1	0.1%	х			
241	Caregiver's burden	1	0.1%			x	
242	Good physical care	1	0.1%		Х		
243	End-of-life care needs	1	0.1%			x	
244	Headache	1	0.1%	х			
	Need for more medical care						
245	support	1	0.1%			X	
246	Vaginal discharge Need for more nursing support	1	0.1%	Х			
						Х	
247	at night	1	0.1%			^	
247 248	at night Adverse events	1 1	0.1% 0.1%			^	х
248	at night Adverse events Need for more psychological	1	0.1%				х
248 249	at night Adverse events Need for more psychological support	1	0.1% 0.1%			x	х
248	at night Adverse events Need for more psychological support Visits from social work	1	0.1%				х
248 249	at night Adverse events Need for more psychological support	1	0.1% 0.1%			x	х
248 249 250	at night Adverse events Need for more psychological support Visits from social work Need for more support for	1 1 1	0.1% 0.1% 0.1%	x		x x	х
248249250251	at night Adverse events Need for more psychological support Visits from social work Need for more support for personal care	1 1 1	0.1% 0.1% 0.1% 0.1%	x x		x x	х
248249250251252	at night Adverse events Need for more psychological support Visits from social work Need for more support for personal care Vital signs when in opioids	1 1 1 1	0.1% 0.1% 0.1% 0.1% 0.1%			x x	x
248249250251252253	at night Adverse events Need for more psychological support Visits from social work Need for more support for personal care Vital signs when in opioids Neurological symptoms	1 1 1 1 1	0.1% 0.1% 0.1% 0.1% 0.1%	x		x x	х

	Grand Total	1951	100%	337	428	1180	6
257	ICD shocks	1	0.1%				x
256	Caregiver's need for more psychological support	1	0.1%			x	