KCE REPORT 394S

Federaal Kenniscentrum voor de Gezondheidszorg
Centre Fédéral d'Expertise des Soins de Santé
Belgian Health Care Knowledge Centre

PROPOSITIONS FOR REINFORCING AND EXPANDING THE BELGIAN PALLIATIVE CARE OFFER: THE RIGHT CARE AT THE RIGHT MOMENT AT THE RIGHT PLACE

SUPPLEMENT





KCE REPORT 394S
HEALTH SERVICES RESEARCH

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SUPPLEMENT

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COLOPHON

Title:	Propositions for reinforcing and expanding the Belgian palliative care offer: the right care at the right moment at the right place – Supplement
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Cormann (Fachbereichsleiterin Gesundheit und Senioren), Stephanie Kuckart (Fachbereichsleiterin Gesundheit und Senioren)

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Acknowledgements: We would like to thank our colleagues at KCE for their inputs and support during this project: Carl Devos, Laurence Kohn, Roos Leroy, Jens Detollenaere, Céline Pouppez, Koen Van den Heede, Emily Van Coolput, Els Van Bruystegem and Andrée Mangin.

We would like to address a special thanks to the directors and staff of the three Federations of Palliative Care for their availability in answering our numerous questions and the fruitful discussions during this project. We also would like to thank the members of the patient umbrella associations and informal caregivers associations, the hospital federations, the professional associations of GP, specialists and nurses who commented on the proposal in September 2024.

Finally, last but not least, we would like to thank all the stakeholders, professionals and volunteers who participate to this study, especially those who welcomed our team in their service during our site visits.

Reported interests KCE members: KCE is a federal institution funded by INAMI-RIZIV, by the Federal Public Service of Health, Food chain Safety and Environment, and by the Federal Public Service of Social Security. KCE's mission is to advise policymakers on decisions relating to health care and health insurance on the basis of scientific and objective research. It is expected to identify and shed light on the best possible solutions, in the context of an accessible, high-quality healthcare system with due regard for growing demand and budgetary constraints.

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Reported interests: All experts and stakeholders consulted within this report were selected because of their involvement in the topic of palliative care. Therefore, by definition, each of them might have a certain degree of conflict of interest to the main topic of this report.

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Publication date:	16 January 2025
Project number:	2022-02
Domain:	Health Services Research (HSR)
MeSH:	Palliative care; Palliative Medicine; Patient Preference; Hospice care; Belgium
NLM Classification:	WB 310 Hospice care. Palliative care. Terminal care
Language:	English
Format:	Adobe® PDF™ (A4)
Legal depot:	D/2024/10.273/64
ISSN:	2466-6459
Copyright:	KCE reports are published under a “by/nc/nd” Creative Commons Licence http://kce.fgov.be/content/about-copyrights-for-kce-publications.
How to refer to this document?	Dauvrin M, Desomer A, Savoye I, Adriaenssens J, Ricour C. Propositions for reinforcing and expanding the Belgian palliative care offer: the right care at the right moment at the right place. Health Services Research (HSR) Brussels: Belgian Health Care Knowledge Centre (KCE). 2024. KCE Reports 394S. D/2024/10.273/64. This document is available on the website of the Belgian Health Care Knowledge Centre. https://doi.org/10.57598/R394S

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LIST OF ABBREVIATIONS

ABBREVIATION	DEFINITION
AHD	*Ambulante hospizdienste - AHD*
AHZN	Associatie voor HospiceZorg Nederlands
ANESM	*Agence Nationale de l'Évaluation et de la Qualité des Établissements et Services Sociaux et Médico-sociaux*
ARS	*Agences regionals de santé*
BHT	*Bijna Thuis Huizen*
CMO	*Concertation multidisciplinaire d'oncologie*
CQC	Care Quality Commission
DGP	*Deutsche Gesellschaft für Palliativmedizin*
DHPV	*Deutscher Hospiz- und PalliativVerbandes*
DKG	*Deutsche Krebsgesellschaft*
DCP	Delivering Choice Programme
DSHV	*Deutsche Stiftung Hospiz und Palliativ Versorgung*
EAPC	European Association for Palliative Care
EBP	Evidence-based practice
EHPAD	*Etablissement d'hébergement pour personnes âgées dépendantes*
EHPA	*Etablissement d'hébergement pour personnes âgées*
EMSP	*Equipes mobiles de soins palliatifs*
EOL	End of Life
ERRSPP	*Equipes ressources régionales de soins palliatifs pédiatriques*
GP	General Practitioner
HAD	*Hospitalisation à domicile*
HAH	Hospitalisation at home

HAS	*Haute Autorité de Santé*
HCH	High Care Hospice
HDJ	*Hôpital de jour*
HOPE	Hospice and Palliative Care Evaluation
IKNL	*Integraal Kankercentrum Nederland*
KWF	*Koningin Wilhelmina Fonds*
LISP	*Lits identifiés de soins palliatifs*
LTCF	Long-Term Care Facility
MDO	*Multidisciplinair overleg*
NFK	*Federatie van Kankerpatiënten Organisaties*
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
PC	Palliative Care
PCU	Palliative Care Unit
PTZ	*Palliatieve Terminale Zorg*
PU	Palliative unit
SAPV	*Spezialisierte ambulante Palliativversorgung*
SFAP	*Société Française d'Accompagnement et de Soins Palliatifs*
UK	United Kingdom
UNASP	*Union Nationale pour l'Accompagnement en Soins Palliatifs*
USLD	*Unité de soins de longue durée*
USP	*Unités de soins palliatifs*
WTZ	*Wet Toetreding Zorginstellingen*
WLZ	*Wet Langdurige Zorg*

WMO	*Wet Maatschappelijke Ondersteuning*
ZVW	*Zorgverzekeringwet*

1 APPENDIX I - SEARCH STRATEGIES EFFECTIVENESS

1.1 Cochrane

Date	21/02/2024 21:50:55	
Database	Cochrane	
Search strategy		
#1	[mh ^"Palliative Care"]	2586
#2	[mh ^"Palliative Medicine"]	4
#3	[mh "palliative therapy"]	2586
#4	[mh ^"Hospice and Palliative Care Nursing"]	97
#5	[mh ^"Hospice Care"]	173
#6	[mh ^"Terminal Care"]	542
#7	#1 or #2 or #3 or #4 or #5 or #6	3059
#8	palliative:ab,ti,so	7989
#9	hospice?:ti,so	351
#10	end-of-life:ti,so	497
#11	(terminal NEAR/3 (care or illness or disease or support or cancer)):ti,kw	1052
#12	"terminally ill":ti,kw	280
#13	(bereavement NEAR/3 (care or support or program?)):ti,kw	65
#14	dying:ti,kw	188
#15	(symptom? NEAR/1 control):ti,kw	280
#16	(advanced NEAR/3 (disease? or illness*)):ti,kw	1395
#17	(incurable NEAR/3 (disease? or illness*)):ti,kw	5
#18	(end-stage NEAR/3 (disease? or illness*)):ti,kw	3494
#19	"close to death":ti,kw	0
#20	#8 or #9 or #10 or #11 or #12 or #13 or #14 or #15 or #16 or #17 or #18 or #19	14011
#21	#7 or #20	14938

#22	[mh ^"Comparative Effectiveness Research"]	490
#23	[mh ^"efficiency, organisational"]	175
#24	[mh ^"Efficiency"]	449
#25	[mh ^"Cost-Effectiveness Analysis"]	88
#26	#22 or #23 or #24 or #25	1198
#27	efficient:ab,ti,kw	16833
#28	efficiency:ab,ti,kw	22865
#29	effectiveness:ab,ti,kw	208148
#30	"effect on":ti,kw	347645
#31	"effect of":ti,kw	202685
#32	#27 or #28 or #29 or #30 or #31	552751
#33	#26 or #32	552751
#34	#21 and #33	4529
#35	#34 with Cochrane Library publication date Between Jan 2013 and Feb 2024	3947
#36	#35 in Cochrane Reviews	49
Comments		

1.2 Embase

Date	**21 Feb 2024**	
Database	Embase	
Search strategy		
#1	'palliative therapy'/exp	147644
#2	'palliative nursing'/de	1743
#3	'hospice care'/de	13828
#4	'terminal care'/exp	88522
#5	#1 OR #2 OR #3 OR #4	212890
#6	palliative:ti,kw,jt	85251

#7	hospice$:ti,kw,jt	15251
#8	'end of life':ti,kw,jt	25723
#9	(terminal NEAR/3 (care OR illness OR disease OR support OR cancer)):ti,kw,jt	5314
#10	'terminally ill':ti,kw	2694
#11	(bereavement NEAR/3 (care OR support OR program$)):ti,kw,jt	764
#12	dying:ti,kw	12528
#13	(symptom$ NEAR/1 control):ti,kw	1374
#14	(advanced NEAR/3 (disease$ OR illness*)):ti,kw	9208
#15	(incurable NEAR/3 (disease$ OR illness*)):ti,kw	201
#16	('end stage' NEAR/3 (disease$ OR illness*)):ti,kw	25937
#17	'close to death':ti,kw	22
#18	#6 OR #7 OR #8 OR #9 OR #10 OR #11 OR #12 OR #13 OR #14 OR #15 OR #16 OR #17	153467
#19	#5 OR #18	279571
#20	'comparative effectiveness'/de	150306
#21	'organisational efficiency'/de	1263
#22	'cost effectiveness analysis'/de	187169
#23	#20 OR #21 OR #22	334671
#24	efficiency:ab,ti,kw	708560
#25	efficient:ab,ti,kw	733818
#26	effectiveness:ab,ti,kw	830226
#27	'effect on':ti	75726
#28	'effect of':ti	1108239
#29	#24 OR #25 OR #26 OR #27 OR #28	3245971
#30	#23 OR #29	3427715
#31	#19 AND #30	17446
#32	#31 AND ('meta-analysis'/exp OR 'meta-analysis' OR 'systematic review'/exp OR 'systematic review')	1664
#33	#32 NOT ('conference abstract'/it OR 'conference paper'/it OR 'conference review'/it)	1261

#34	#33 AND [2013-2024]/py	1010
#35	#34 NOT [medline]/lim	203
Comments		

1.3 Medline

Date	**February 16, 2024**	
Database	Ovid MEDLINE(R) and Epub Ahead of Print, In-Process, In-Data-Review & Other Non-Indexed Citations, Daily and Versions <1946 to February 16, 2024>	
Search strategy		
1	Palliative Care/	64293
2	exp palliative therapy/	64293
3	"Hospice and Palliative Care Nursing"/	2528
4	Palliative Medicine/	556
5	Terminal Care/	32301
6	Hospice Care/	8238
7	1 or 2 or 3 or 4 or 5 or 6	92345
8	palliative.ti,kf,jw.	59185
9	hospice?.ti,kf,jw.	12227
10	end-of-life.ti,kf,jw.	19176
11	(terminal adj3 (care or illness or disease or support or cancer)).ti,kf,jw.	4021
12	terminally ill.ti,kf.	2293
13	(bereavement adj3 (care or support or program?)).ti,kf,jw.	587
14	dying.ti,kf.	10573
15	symptom? control.ti,kf.	721
16	(advanced adj3 (disease? or illness*)).ti,kf.	5973
17	(incurable adj3 (disease? or illness*)).ti,kf.	153
18	(end-stage adj3 (disease? or illness*)).ti,kf.	17864

19	close to death.ti,kf.	18
20	8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19	110021
21	7 or 20	149531
22	Comparative Effectiveness Research/	4007
23	efficiency, organisational/	22453
24	Efficiency/	15784
25	Cost-Effectiveness Analysis/	751
26	22 or 23 or 24 or 25	42649
27	efficient.ab,ti,kf.	637323
28	efficiency.ab,ti,kf.	620541
29	effectiveness.ab,ti,kf.	624221
30	effect on.ti,kf.	61580
31	effect of.ti,kf.	1068617
32	27 or 28 or 29 or 30 or 31	2760569
33	26 or 32	2788808
34	21 and 33	7765
35	limit 34 to systematic reviews	585
36	limit 35 to yr="2013-2024"	469
37	"Delivery of Health Care"/	121351
38	36 and 37	8
39	Palliative Care/	64293
40	Palliative Medicine/	556
41	exp palliative therapy/	64293
42	"Hospice and Palliative Care Nursing"/	2528
43	Hospice Care/	8238
44	39 or 40 or 41 or 42 or 43	70233
45	palliative.ab,ti,kf,jw.	99389

46	end-of-life.ab,ti,kf,jw.	33129
47	(hospice adj2 care).ab,ti,kf,jw.	6409
48	45 or 46 or 47	119285
49	44 or 48	142399
50	continuity of patient care/	20806
51	Rural Health Services/	14106
52	Community Health Workers/	6752
53	exp Home Care Services/	51275
54	50 or 51 or 52 or 53	90714
55	outreach.ab,ti,kf.	19165
56	community.ti,kf.	214565
57	rural.ti,kf.	82278
58	mobile team.ti,kf.	58
59	home-based.ti,kf.	5975
60	delivery.ti,kf.	190299
61	undeserved population.ti,kf.	2
62	mobile team?.ti,kf.	82
63	55 or 56 or 57 or 58 or 59 or 60 or 61 or 62	495317
64	54 or 63	565795
65	49 and 64	8015
66	limit 65 to yr="2013-2024"	4308
67	limit 66 to systematic reviews	145
68	Efficiency/	15784
69	efficiency, organisational/	22453
70	Cost-Effectiveness Analysis/	751
71	Comparative Effectiveness Research/	4007
72	68 or 69 or 70 or 71	42649

73	efficiency.ab,ti,kf.	620541
74	efficient.ab,ti,kf.	637323
75	effectiveness.ab,ti,kf.	624221
76	effect on.ti,kf.	61580
77	effect of.ti,kf.	1068617
78	73 or 74 or 75 or 76 or 77	2760569
79	72 or 78	2788808
80	66 and 79	357
81	limit 80 to systematic reviews	33
82	36 and 81	29
83	81 not 82	4
84	(palliative or hospice? or end-of-life or (terminal adj3 (care or illness or disease or support or cancer)) or terminally ill or (bereavement adj3 (care or support or program?)) or dying or symptom? control or (advanced adj3 (disease? or illness*)) or (incurable adj3 (disease? or illness*)) or (end-stage adj3 (disease? or illness*)) or close to death).ab.	235061
85	7 or 84	281900
86	33 and 85	16508
87	limit 86 to systematic reviews	945
88	limit 87 to yr="2013-2024"	673
89	81 and 88	32
90	81 not 88	1
91	remove duplicates from 36	464
Comments		

2 APPENDIX II - SEARCH STRATEGIES ACCEPTABILITY

2.1 Cochrane

Date	22/05/2023 06:20:54	
Database	Cochrane	
Search strategy		
#1	[mh ^"Hospices"]	63
#2	hospice?:ab,ti	903
#3	"palliative care settings":ab,ti	31
#4	"palliative care facility":ab,ti	3
#5	"palliative care facilities":ab,ti	5
#6	#2 or #3 or #4 or #5	936
#7	#1 or #6	939
#8	[mh ^"patient satisfaction"]	14739
#9	[mh ^"Intention"]	1431
#10	[mh /PX]	70304
#11	[mh ^"Attitude"]	1493
#12	[mh ^"Perception"]	2447
#13	[mh ^"Motivation"]	6490
#14	[mh ^"Attitude to Health"]	3382
#15	[mh ^"Health Knowledge, Attitudes, Practice"]	7384
#16	[mh ^"Health Behavior"]	5236
#17	[mh ^"Models, Psychological"]	1453
#18	[mh ^"Psychological Theory"]	673
#19	[mh ^"Decision making"]	3598
#20	[mh ^"Theory of Planned Behavior"]	20
#21	#8 OR #9 OR #10 OR #11 OR #12 OR #13 OR #14 OR #15 OR #16 OR #17 OR #18 OR #19 OR #20	98049

#22	satisfaction:ab,ti	55467
#23	preference?:ab,ti	18041
#24	(patient? NEAR/3 value*):ab,ti	5641
#25	(attributes NEAR/2 care):ab,ti	12
#26	(patient? NEAR/3 views):ab,ti	450
#27	"social support":ab,ti	6661
#28	(patient? NEAR/2 perception?):ab,ti	3323
#29	(patient? NEAR/2 expectation?):ab,ti	828
#30	barriers:ab,ti	14867
#31	(patient? NEAR/2 intentions):ab,ti	36
#32	perception?:ab,ti	29275
#33	intention?:ab,ti	40419
#34	attitude?:ab,ti	15629
#35	"Theory of planned behavior":ab,ti	714
#36	#22 OR #23 OR #24 OR #25 OR #26 OR #27 OR #28 OR #29 OR #30 OR #31 OR #32 OR #33 OR #34 OR #35	163815
#37	#21 OR #36	231663
#38	#7 AND #37	384
#39	#38 with Cochrane Library publication date Between Jan 2013 and Dec 2023	321
#40	#39 in Cochrane Reviews	4
Comments		

2.2 Cinahl

Date	Friday, June 02, 2023 8:53:30 AM	
Database	Cinahl	
Search strategy		
S1	(MH "Hospices")	3,346
S2	(AB hospice#) or (TI hospice#)	14,232
S3	(AB "palliative care settings") or (TI "palliative care settings")	394
S4	(AB "palliative care facility") or (TI "palliative care facility")	22
S5	(AB "palliative care facilities") or (TI "palliative care facilities")	33
S6	S2 or S3 or S4 or S5	14,570
S7	S1 or S6	15,615
S8	(MH "Patient Satisfaction")	60,933
S9	(MH "Intention")	10,191
S10	(MH "Attitude")	17,540
S11	(MH "Perception")	30,978
S12	(MH "Motivation")	45,767
S13	(MH "Attitude to Health")	48,786
S14	(MH "Health Knowledge")	36,388
S15	(MH "Health Behavior")	57,737
S16	(MH "Models, Psychological")	10,175
S17	(MH "Psychological Theory")	11,368
S18	(MH "Decision Making, Patient+")	19,905
S19	(MH "Decision Making, Family")	4,192
S20	(MH "Ajzen's Theory of Planned Behavior")	2,458
S21	(MH "Decision Making")	57,588
S22	S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21	363,667
S23	(AB satisfaction) or (TI satisfaction)	94,412

S24	(AB preference#) or (TI preference#)	50,021
S25	(AB (patient# N3 value*)) or (TI (patient# N3 value*))	18,189
S26	(AB (attributes N2 care)) or (TI (attributes N2 care))	452
S27	(AB (patient# N3 views)) or (TI (patient# N3 views))	5,759
S28	(AB "social support") or (TI "social support")	32,988
S29	(AB (patient# N2 perception#)) or (TI (patient# N2 perception#))	11,398
S30	(AB (patient# N2 expectation#)) or (TI (patient# N2 expectation#))	4,543
S31	(AB barriers) or (TI barriers)	115,511
S32	(AB (patient# N2 intentions)) or (TI (patient# N2 intentions))	836
S33	(AB perception#) or (TI perception#)	151,141
S34	(AB intention#) or (TI intention#)	39,613
S35	(AB attitude#) or (TI attitude#)	97,251
S36	(AB "Theory of planned behavior") or (TI "Theory of planned behavior")	2,160
S37	S23 OR S24 OR S25 OR S26 OR S27 OR S28 OR S29 OR S30 OR S31 OR S32 OR S33 OR S34 OR S35 OR S36	517,487
S38	S22 OR S37	756,857
S39	S7 AND S38	3,566
S40	(TI (systematic* n3 review*)) or (AB (systematic* n3 review*)) or (TI (systematic* n3 bibliographic*)) or (AB (systematic* n3 bibliographic*)) or (TI (systematic* n3 literature)) or (AB (systematic* n3 literature)) or (TI (comprehensive* n3 literature)) or (AB (comprehensive* n3 literature)) or (TI (comprehensive* n3 bibliographic*)) or (AB (comprehensive* n3 bibliographic*)) or (TI (integrative n3 review)) or (AB (integrative n3 review)) or (JN “Cochrane Database of Systematic Reviews”) or (TI (information n2 synthesis)) or (TI (data n2 synthesis)) or (AB (information n2 synthesis)) or (AB (data n2 synthesis)) or (TI (data n2 extract*)) or (AB (data n2 extract*)) or (TI (medline or pubmed or psyclit or cinahl or (psycinfo not “psycinfo database”) or “web of science” or scopus or embase)) or (AB (medline or pubmed or psyclit or cinahl or (psycinfo not “psycinfo database”) or “web of science” or scopus or embase)) or (MH “Systematic Review”) or (MH “Meta Analysis”) or (TI (meta-analy* or metaanaly*)) or (AB (meta-analy* or metaanaly*))	284,379
S41	S39 AND S40	193
S42	S41 - Exclude MEDLINE records	122
S43	S42 - Published Date: 20130101-20231231	105

Comments

2.3 Embase

Date	22 May 2023	
Database	Embase	
Search strategy		
#1	'hospice'/de	17690
#2	hospice$:ab,ti	26624
#3	'palliative care settings':ab,ti	757
#4	'palliative care facility':ab,ti	50
#5	'palliative care facilities':ab,ti	79
#6	#2 OR #3 OR #4 OR #5	27257
#7	#1 OR #6	30469
#8	'patient satisfaction'/de	166242
#9	'attitude'/de	75967
#10	'perception'/de	163452
#11	'motivation'/exp	171200
#12	'attitude to health'/de	131562
#13	'health behavior'/de	78746
#14	'psychological model'/de	28438
#15	'psychological theory'/de	13886
#16	'patient decision making'/de	11815
#17	'family decision making'/de	1678
#18	'shared decision making'/de	13945
#19	'theory of planned behavior'/de	2615
#20	#8 OR #9 OR #10 OR #11 OR #12 OR #13 OR #14 OR #15 OR #16 OR #17 OR #18 OR #19	791805
#21	satisfaction:ab,ti	244777

#22	preference$:ab,ti	231780
#23	(patient$ NEAR/3 value*):ab,ti	79435
#24	(attributes NEAR/2 care):ab,ti	298
#25	(patient$ NEAR/3 views):ab,ti	6629
#26	'social support':ab,ti	62238
#27	(patient$ NEAR/2 perception$):ab,ti	25651
#28	(patient$ NEAR/2 expectation$):ab,ti	10666
#29	barriers:ab,ti	236865
#30	(patient$ NEAR/2 intentions):ab,ti	325
#31	perception$:ab,ti	392535
#32	intention$:ab,ti	110951
#33	attitude$:ab,ti	234667
#34	'theory of planned behavior':ab,ti	3302
#35	#21 OR #22 OR #23 OR #24 OR #25 OR #26 OR #27 OR #28 OR #29 OR #30 OR #31 OR #32 OR #33 OR #34	1412061
#36	#20 OR #35	1847561
#37	#7 AND #36	6681
#38	#37 AND ('meta-analysis'/exp OR 'meta-analysis' OR 'systematic review'/exp OR 'systematic review')	240
#39	#38 NOT [medline]/lim	100
#40	#39 NOT ('conference abstract'/it OR 'conference paper'/it OR 'conference review'/it)	16
#41	#40 AND [2013-2023]/py	13
Comments		

2.4 PsycInfo

Date	May Week 4 2023	
Database	APA PsycInfo <2002 to May Week 4 2023>	
Search strategy		
1	Hospice/	2936
2	hospice?.ab,id,ti.	4830
3	"palliative care settings".ab,id,ti.	241
4	"palliative care facility".ab,id,ti.	9
5	"palliative care facilities".ab,id,ti.	11
6	2 or 3 or 4 or 5	5006
7	1 or 6	5078
8	client satisfaction/	5082
9	exp intention/	19554
10	attitudes/	18289
11	client attitudes/	13255
12	perception/	14442
13	motivation/	44873
14	Health Attitudes/	7381
15	Health Knowledge/	7686
16	health behavior/	25845
17	psychological theories/	6546
18	decision making/	71546
19	exp choice behavior/	42635
20	reasoned action/	2856
21	8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20	254104
22	satisfaction.ab,id,ti.	92717
23	preference?.ab,id,ti.	80085

24	(patient? adj3 value*).ab,id,ti.	3136
25	(attributes adj2 care).ab,id,ti.	78
26	(patient? adj3 views).ab,id,ti.	1364
27	"social support".ab,id,ti.	44943
28	(patient? adj2 perception?).ab,id,ti.	4652
29	(patient? adj2 expectation?).ab,id,ti.	1333
30	barriers.ab,id,ti.	67941
31	(patient? adj2 intentions).ab,id,ti.	90
32	perception?.ab,id,ti.	259684
33	intention?.ab,id,ti.	59297
34	attitude?.ab,id,ti.	157207
35	"Theory of planned behavior".ab,id,ti.	4560
36	Reasoned Action.ab,ti,id.	1291
37	22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36	642917
38	21 or 37	788517
39	7 and 38	1684
40	limit 39 to systematic reviews	68
41	limit 40 to yr="2013-2023"	58
Comments		

Hospices/

hospice?.ab,ti,kf

palliative care settings.ab,ti,kf

palliative care facility.ab,ti,kf

palliative care facilities.ab,ti,kf

2 or 3 or 4 or 5

1 or 6

patient satisfaction/
Intention/
px.xs
Attitude/
Perception/
Motivation/
Attitude to Health/
Health Knowledge, Attitudes, Practice/
Health Behavior/
Models, Psychological/
Psychological Theory/
Decision making/
Theory of Planned Behavior/
8 OR 9 OR 10 OR 11 OR 12 OR 13 OR 14 OR 15 OR 16 OR 17 OR 18 OR 19 OR 20
satisfaction.ab,ti,kf
preference?.ab,ti,kf
(patient? adj3 value*).ab,ti,kf
(attributes adj2 care).ab,ti,kf
(patient? adj3 views).ab,ti,kf
social support.ab,ti,kf
(patient? adj2 perception?).ab,ti,kf
(patient? adj2 expectation?).ab,ti,kf
barriers.ab,ti,kf
(patient? adj2 intentions).ab,ti,kf

perception?.ab,ti,kf

intention?.ab,ti,kf

attitude?.ab,ti,kf

"Theory of planned behavior".ab,ti,kf

22 OR 23 OR 24 OR 25 OR 26 OR 27 OR 28 OR 29 OR 30 OR 31 OR 32 OR 33 OR 34 OR 35

21 OR 36

7 AND 37

limit 38 to yr-"2013-2023"

limit 39 to systematic reviews

3 APPENDIX III - EVIDENCE TABLES RELATED TO PREFERRED PLACE OF DEATH

Badrakalimuthu et al., Do people with dementia die at their preferred location of death? A systematic literature review and narrative synthesis, 2014[3]	
Type + number of included studies	N= 6 studies, search 1985-2013
Type of participants (+ setting)	People with dementia >65y old
Intervention vs comparator	(preferred) place of death
Primary outcomes	**Place of death (based on death certificates)** • all 3 studies report death in dementia to be more common in care homes than other locations, with variation in place of death across European countries. • patients enrolled in a home hospice programme for dementia: increased patients dying at their preferred location of death **Factors influencing location of death** • older age, male gender, availability of hospital were associated with hospital deaths • availability of nursing home beds was associated with death in nursing home • enrolment in hospice was associated with deaths in own residence **Patients' preference for place of death** • those enrolled with the home hospice for dementia were more likely to die at their location of choice and less likely to die in hospital (n= 1 small study) • in one study: 14 residents preferred to die in group home (42%), 15 preferred home (46%) and none preferred hospital. The authors of the primary study state that only 6 patients had died at their preferred place of death.
Secondary outcomes	**Family caregivers' and healthcare professionals preference for location of death** • the paper reports that in 32 out of 33 cases the wishes of family members for place of death was achieved but provides no information concerning what locations the family members had preferred (n= 1 small study) • no study was found on the HC professionals preferred location of death for patients with dementia
Authors' conclusion	This review reveals that while there is some knowledge concerning place of death for people with dementia, very little is known about patient, family carer and health professional preferences or the extent to which patients discuss their preferences with their families and healthcare professionals. Studies of death certificate data show that patients with dementia die more commonly in care homes than other locations: in contrast, prospective studies show that death is more common in own residence or hospital. In the only study that looked at preferences it appears that preferences of proxy decision-makers are met more often than those of the patients themselves.
comments	/

Costa et al., The determinants of home and nursing home death: a systematic review and meta-analysis, 2016[5]	
Type + number of included studies	N= 26 studies (retrospective, cohort studies), search 2004-2013
Type of participants (+ setting)	Adult patients with an advanced, life-limiting condition, in Canada, Asia, Europe, US, Mexico, New Zealand
Intervention vs comparator	Determinants of home or nursing home death compared to hospital death: type of disease, symptoms such as pain, hospital admissions, functional status, availability of home care, palliative care in the place of residence, patient and/or family preference for place of death, living arrangements, presence, and support for informal caregivers.
Primary outcomes	**(preferred) Place of death** • Home death occurred in 21 % to 78 % of the patients. • Four studies stated a preference: 26 % to 85 % of patients preferred a home death, as did 45 % to 65 % of family members. **Determinants of home death** • Factors associated with an increased likelihood of home death: nurse and family physician home visits, multidisciplinary home palliative care, patient and family preference for home death, cancer compared to other diseases, timing of referral to palliative care, worse functional status, not living alone, presence of an informal caregiver, and caregiver coping. • Factors that decreased the likelihood of home death: hospital admissions in the last year of life, admission to a hospital with palliative care services, and some diseases such as cardiovascular versus other diseases and haematological cancers compared to solid tumours. **Determinants of nursing home death** • Factors that were associated with an increased likelihood of nursing home death: palliative care services available in the nursing home, having completed an advance directive, patient or family preference for nursing home death, some diseases such as dementia, stroke and end-stage disease, functional status, admission to a hospital-based nursing home, and a longer duration of stay at the nursing home.
Secondary outcomes	/
Authors' conclusion	Place of death may not be a very good indicator of the quality of end-of-life/palliative care since it is determined by multiple factors and is therefore dependent on individual circumstances. Some factors identified in our analyses are related to the illness and may not be modifiable, for instance type of disease, living arrangements, and the presence of symptoms that result in frequent hospital admissions. However, it may still be important to keep these factors in mind when discussing the feasibility of dying in the location of preference with patients and family members. On the other hand, if feasible, some of the factors identified can be acted upon to improve the likelihood that the patient's preferences will be met. Modifiable factors include the presence of a multidisciplinary palliative care team in the home and the availability of palliative care services in the nursing home, providing support to the patient and caregiver, and a timely referral to palliative care services.
comments	/

Fereidouni et al., Preferred place of death in adult cancer patients: a systematic review and meta-analysis, 2021[1]	
Type + number of included studies	Search up to 2020, n= 27 included studies (observational studies (cohort studies, cross-sectional studies, case-control studies) with focus on cancer patients, published in English)
Type of participants (+ setting)	Adult cancer patients (no selection made on race, gender, or ethnicity), Asia, the Americas, Europe, Africa, and Australia
Intervention vs comparator	Preferred place of death versus actual place of death, and factors influencing their choice
Primary outcomes	**Prevalence preferred place of death:** • home: 55% of cancer patients [95%CI 61-49] (n=27 studies) • hospital: 17% of cancer patients [95% CI 12-23] (n=21 studies) • hospice: 10% of cancer patients [95% CI 8-13] (n=12 studies) **Factors influencing the choice of preferred place of death:** • demographic characteristics: ○ age: (contradictory results) younger patients more likely to choose hospital (n=1 study) vs to choose home as PPOD (n=1 study). Older patients chose home as PPOD (n=1 study). ○ Gender: women were less likely to choose home as PPOD (1 study) and women more likely to discuss on PPOD (n=1 study) ○ Level of education: patients with lower level of education whose home as PPOD (n=2 studies) ○ Area of residence: patients living in rural areas chose home as PPOD (n=1 study) ○ Status of life: patients living with family members were more likely to choose home (n=1 study), patients living alone were less likely to choose home as PPOD (n=1 study). Married people more likely to choose home as PPOD (n= 1 study) ○ Race: white patients more likely to choose home as PPOD (vs Black patients) (n=1 study) • Disease-related factors: ○ Type of cancer (3): patients with liver and pancreatic cancer (n=1 study) and with lung or breast cancer (n= 1 study) more likely to choose home as PPOD ○ Time of diagnosis (2): patient in poor physical condition and survived for more than 6 months more likely to choose home. ○ Prognosis of disease: patients who knew their prognosis less likely to choose home as PPOD (n=1 study) ○ Patient symptoms: patients with severe to moderate pain less likely to choose home as PPOD (n=1 study) ○ Medical treatment: patients using morphine to relieve pain more likely to choose home (n=1 study) ○ Disease awareness: patients who were aware of their illness more likely to choose home (n=2 studies) ○ Satisfaction with treatment: patients who were satisfied with their treatment more likely to choose home (n=1 study) ○ Functional status: patients with better and more independent functional status less likely to choose home (n=1 study) • Psychosocial factors: no meta-analysis could be performed due to heterogeneity between studies, results do not necessarily indicate a specific direction and cause. ○ Not imposing burden on family and other caregivers (4) ○ Patients' level of anxiety (1)

	○ Awareness of incurability of the disease (1) ○ Participation or non-participation of social workers (1) ○ Being with family in the last days of life (1) ○ Having independence in doing daily tasks at end-of-life (2) ○ Environmental security (1) ○ Intimacy and emotional connection with family members (1)
Secondary outcomes	In discussion: • Preference for place of care and place of death is not a fixed concept and can change over time through discussion between HC professionals and patients. • Vidal et al., 2020: significant number of patients have no preference or prefer to die in hospital, especially in patients who have already examined home care, have financial and social problems, or have uncontrolled physical and mental symptoms and distress. • In many countries number of deaths at home is declining and guidelines have been developed to reduce deaths at home
Authors' conclusion	Based on the results of the present study, more than half of cancer patients in the later stages of life prefer to die at home. Considering that one of the goals of palliative care and end-of-life care program is to increase the quality of life of patients and their families, for this reason, guided policies to ensure death of patients in the desired place according to the patient's condition should be priority. Therefore, HC professionals should be aware of the palliative care needs of patients.
Comments	In introduction: role of social norms in determining place of death. First period, people often died at home due to poor access to health resources, secondly more deaths in hospitals due to advances in health system and in last decade preference to die at home, with emphasis on quality of end-of-life care and by developing home care. Only qualitatively reporting on psychosocial factors due to severe heterogeneity between studies: difficult to estimate the direction of relationship between those factors and PPOD

Garcia-Sanjuan et al., Levels and determinants of place-of-death congruence in palliative patients: a systematic review, 2022[7]	
Type + number of included studies	N=30 studies (n=19 retrospective observational studies, n=8 prospective observational studies, n= 1 RTC, n=1 mixed study), search 2010-2021
Type of participants (+ setting)	Patients at the end of life, populations over 18years of age with both oncological and non-oncological pathologies
Intervention vs comparator	Congruence, defined as the agreement between the patient's preferred place of death and their actual place of death, and the factors identified as determinants of congruence
Primary outcomes	**Preferred place of death:** • preference for hospital (in 23 of 20 studies): ranging from 0% to 33,3% • preference for dying at home (in 29 of 30 studies): ranging from 24% to 78,6% • preference in medium to long stay facilities (in 19 of 30 studies): ranging from 0,8% to 40,8% • preference for dying in a hospice or palliative care unit (in 23 of 30 studies): ranging from 1,4% to 60%.

	Actual place of death (reported in 27 of 30 studies) • in hospital: ranged from 6% to 74,3% (in 24 of 27 studies) • at home: ranged from 13,4% to 88,9% (in all 27 studies) • in medium to long stay facilities: ranged from 0% to 50,9% (in 19 studies) • in hospice or palliative care unit: ranged from 3,2% to 57,2% (in 22 studies) **Congruence index** • overall congruence: ranged from 21% to 100% (in 19 studies) • kappa agreement indices ranging from 0,016 to 0,527 (in 7 studies)
Secondary outcomes	**Factors associated with congruence in place of death (with positive and negative (lack of congruence) associations)** • illness-related factors (reported in 5 studies): ○ patient's functional status had both a positive and negative association with congruence. ○ Cancer diagnosis and stroke were negatively associated with congruence. ○ dementia was positively associated. ○ treatment-related: morphine use and ceiling of treatment of symptomatic relief were positively associated with congruence. • individual factors (reported in 10 studies) ○ patient's level of consciousness during the final few days was negatively associated with congruence. ○ marital status (being in a relationship) was positively associated with congruence as were having a non-working relative and age. ○ Significant variability was found in relation to preference for place of death: ▪ Preference for dying at home, preference for cardiopulmonary resuscitation, and early registration of place of death were negatively associated with congruence. ▪ Preference for dying in a hospice, having discussed preferred place of death with a healthcare professional and having decision-making capacity were positively associated with congruence. ○ Other variables had no clear association, for instance being female, which was both positively and negatively associated. ○ religious belief: being Presbyterian (as opposed to other religions) was negatively associated with congruence. • environmental factors (reported in 7 studies) ○ place of residence and indicators of adequate care by nurses, medical staff, or a caregiver were associated with higher congruence. ○ Other variables associated with higher levels of congruence include the family's role, the caregiver's own preference for place of death, being in a high intensity hospice, using a Rapid Response System (RRS), and access to palliative care. ○ Only the amount of time spent in the study (assessed in number of days) and one of the places of residence in the Gage et al. (2015) study had a negative association with congruence.

TABLE 4 | Summary of the factors affecting congruence.

Enhancing congruence	Decreasing congruence
Illness-related	**Illness-related**
Patient's functional status	Patient's functional status
Dementia	Cancer
Treatment-related aspects	Stroke
	Patient's level of consciousness during last days
Individual	**Individual**
Marital status	Preference for dying at home
Non-working relative	Preference for cardiopulmonary resuscitation
Age	Early registering of place of death
Preference for dying in a hospice	Being female
Having spoken to a healthcare professional about the preferred place of death	Religious beliefs
Decision-making capacity	
Being female	
Environmental	**Environmental**
Place of residence	Place of residence
Indicators of adequate care	Time of participation in the study
Family role	
Caregiver's preference	
High intensity hospice	
Having palliative care	

Source: retrieved from Garcia-Sanjuan et al. 2022

Authors' conclusion

The results of the present review show that, although home remains one of the preferred places of death, previous studies indicate that hospitals are often one of the main places where death occurs.

This review, in comparison with previous studies, shows that treatment-related factors such as physical pain control, marital status, having a non-working relative, age, discussing preferred place of death with a healthcare professional, and caregiver's preference have been associated with higher levels of congruence. Depending on the study, other factors have been associated with either higher or lower congruence, such as the patient's diagnosis, gender, or place of residence. In terms of disease-related factors, the use of morphine and other pain-related treatments were positively associated with congruence between the preferred and actual place of death. As such, both variables may refer to the existence of a palliative intervention, which in many cases will be associated with the patient's end of life preferences having been explored, discussed, understood, and considered. However, the patient's own poorer state of health and unconsciousness at the end of life were negatively associated with congruence in place of death. This could be because, in these cases, the doctor and family are the main responsible for the decision-making process and may not be aware of the patient's own preferences, if the issue has not been addressed beforehand, or that these preferences have been put to one side. In addition, specific diagnoses such as cancer or stroke were negatively associated with congruence in the studies evaluated. In the first case, one possible explanation is that cancer patients

	in advanced stages of the disease, despite greater knowledge of their prognosis, may still die in hospital due to the wider treatment options available. Furthermore, this may also indicate an important shortcoming with respect to effective home care plans, since their effectiveness, a priori, should make it possible for many cancer patients to die in their preferred place
comments	/

Gomes et al., Heterogeneity and changes in preferences for dying at home: a systematic review, 2013[4]	
Type + number of included studies	N= 210 studies, search up to 2011
Type of participants (+ setting)	Adult patients with advanced or severe stages of progressive disease (cancer or non-malignant), in 33 countries
Intervention vs comparator	changes of preference (for place of death) with illness progression
Primary outcomes	**Preferred place of death** • moderate strength evidence that most people preferred dying at home (however consistency of findings amongst high quality studies was <70%) **Preference amongst public, patients and caregivers: in general** • amongst the three groups: >50% preferred dying at home (however wide heterogeneity between studies, in studies on patients) • The evidence on public was found to be strong, with three of four high quality studies from Australia and Spain showing that most of the public preferred home. • The evidence on older people was found to have low strength. There were no high-quality studies reporting the percentage of older people who preferred dying at home. • Qualitative studies on preferences of older people: ○ older people wished they would not have to move from their home. ○ fears of burdening the family and requiring full-time nursing care due to dependency from a chronic limiting illness or while dying ○ Normative and moral values (i.e. cultural and religious beliefs involving death at home), and practical issues also played a role for older people (e.g. family witnessing suffering and having to manage pain and the dying body within the domestic space, concerns with the quality of care at home, presence of professionals in the home, involvement of children in intimate care, poor material conditions at home). **Preference of the public** • most of the public (52% to 92%) preferred dying at home. **Preference of patients and caregivers** • Most patients wished dying at home but there was wide variation (percentages ranging 18% to 100%) • most caregivers preferred their relatives to be at home, with less variation than in studies with patients. • qualitative studies:

	○ complex negotiations between family and patients about moving into a nursing home (often dictated by need rather than preference); the use of the patient's personal historical identity and previous wishes to guide decision-making in the absence of overt preferences; and difficulties for the family in balancing the patient and their own wishes. ○ in some situations, a preference for home was dyadic and equally important to patients and caregivers; the result of a 'mutual pact' or promise to the patient, sometimes made in the context of a hospital admission or involving reciprocate care. ○ Some caregivers expressed a sense of achievement when the patient died at home, whilst others felt lack of choice, guilt, and sorrow, depending on the outcome
Secondary outcomes	**Changes over time** • General public (n=1 study): significant shifts after text and video stories were shown. Participants became more negative about choosing to die at home and more positive about choosing to die in hospice, particularly older participants, or to die in nursing homes. • Patients (n=1 study): a decline in home preferences in realistic circumstances (from 58% to 50%) and an increase in ideal circumstances (from 68% to 72%), amongst 84 terminally ill patients. Other studies also showed a decrease in home preference. **Individual changes** • Patients: the direction of changes varied but was most commonly from hospital to home, home to hospice and from home to hospital. • Caregivers: less than a third of the caregivers changed preference (direction of change not reported) **Qualitative findings on changes over time** • Strong and consistent home preferences from patients and caregivers were reported, but so were cases of changes in preferences from home to institutions and from institutions to home. • Preferences changed from home to institutions due to uncontrolled pain and other symptoms ("she had terrible time breathing", incontinence, mental impairment), acute events (e.g. falls, injuries), treatment of reversible conditions for comfort and to maximize length of life, imminent death, caregivers burden/inability to safely care at home, increased need for care and dependency ("as I cannot go to the loo", "when he discovered he was incapable of being the host in his own home"), "naivety" on what to expect ("I've been watching too much TV, if I had known..."), and possible traumatic effects on children. • Preferences changed from institutions to home due to the recognition that "prognosis was grim", limited beds available ("said she couldn't stay any longer"), unsatisfactory/uncomfortable hospital experiences (e.g. fighting for adequate pain control in hospital), and when assured of support from services at home. **Differences between place of care and place of death** • Inconclusive evidence reported on whether patient preferences for place of care and for place of death differ. • Equally inconclusive findings found on caregivers. • Qualitative studies: ○ A "definite" or "desperate" desire to remain at home as long as possible, with the ultimate hope to die at home or until admission if required, was viewed as dignifying if by the time the move happened the person was not aware of it anymore.

	○ Perceptions of family's ability to care impacted on place of care preferences, whereas consequences of witnessing death at home (e.g. for children) impacted on place of death preferences. Regardless of place of death, some surviving spouses said the value was frequently on the place where most of the terminal care was provided and expressed satisfaction at having mastered the time spent at home
Authors' conclusion	In this systematic review we found numerous studies providing moderate evidence that most people prefer dying at home (this was reported in 75% of 130 studies). We also found, based on 10 studies, that around four fifths of patients did not change preference as their illness progressed. There was, however, wide variation. This was observed even amongst high quality studies. We also found indications that a preference for home may be less frequent amongst lay caregivers and older people with qualitative research suggesting that although home is generally the ideal preference, circumstances may make this seem impossible. Qualitative research also revealed a conceptual distinction between preferring home as the place of care and as the place of death, although the evidence was inconclusive on whether there are statistically significant differences between the two.
comments	Considerable heterogeneity within population groups

Hoare et al., Do Patients Want to Die at Home? A Systematic Review of the UK Literature, Focused on Missing Preferences for Place of Death, 2015[2]	
Type + number of included studies	N= 58 studies (n= 34 research papers, n= 8 poster abstracts, n=9 reports, n=5 letters to editors, n=1 conference abstract, n=1 website report), search 2000-2015
Type of participants (+ setting)	Adults living in the UK, in varied settings (patients or general population)
Intervention vs comparator	Adult UK preferences for place of death
Primary outcomes	**Place of death reported by patients** • A broad consensus across all conditions and the public on preference for home • When missing data were included: consensus amongst participants with different health conditions and between participants and public disappeared (lower % amongst cancer participants, multiple conditions, non-cancer and for those where the disease focus was not stated) **Place of death reported by family members** • also, preference for home death • when missing data were included: home preference markedly reduced **Preference for place of death according to setting** • in care home residents: care home as PPOD • in participants at home or in community: preference for death at home • participants in hospice: lower preference for home, with hospice as second largest preference • in hospital: lowest home preference • participants in multiple settings: home as most frequent PPOD

	• when missing data were included: median preference for home >50% in participants in community, at home. In other groups median preference not higher than 33%. **Trends** • When missing data were excluded home was the majority PPOD of the study population in 53 of 65 reports. • When missing data were included, home was the majority PPOD of the study population in only 36 of 65 reports. Studies of the public reported little missing data and consistently reported home as the most preferred place of death, with preference for home across these studies only ranging by 19 percentage points
Secondary outcomes	/
Authors' conclusion	It is unknown what proportion of patients prefers to die at home or elsewhere. Reported preferences for place of death often exclude the views of those with no preference or not asked: when 'missing data' are included, they supress the proportion of preferences for all locations. Caution should be exercised if asserting that most patients prefer to die at home. Preferences for place of death appeared to largely reflect where participants were cared for but not necessarily their medical diagnosis. Participant preferences for home seemed to be far more heterogeneous than those expressed by the public, as demonstrated by the wide range of different values for home preference by participants. Neither the public nor family caregivers appeared to be accurate proxies for patients' preferences for place of death
Comments	To explore the impact of 'missing data,' these spreadsheets were then reproduced with preference percentages including participants whose preferences were either not recorded in the study or not reported in the paper. The 'missing' preferences were included as a discrete category since they could not accurately be included in any of the other pre-existing preference categories. The 'missing' preferences are likely to represent preferences that were not asked or not expressed. Preferences may have been missing because participants may not have been given the opportunity to state their preference, and so could reflect the difficulty healthcare professionals have in holding EOLC conversations. Preferences may also be missing because participants did not have a preference to give. Missing preferences like these suggest that participants prioritised other EOLC issues such as pain and symptom management over place of death. Participants may also have been excluded from analysis because they; were undecided about where they wished to die, did not wish to talk about preferences for place of death, were impaired cognitively or physically from communicating their preference or did not have their preference recorded. Regardless of the reasons, the exclusion of 'missing' preferences from study reporting inflates the significance of recorded preferences

Rainsford et al., Place of death in rural palliative care: A systematic review, 2016[6]	
Type + number of included studies	N= 25 studies (quantitative, qualitative, and mixed methods), search up to 2014
Type of participants (+ setting)	rural, regional, or remote palliative residents, in 21 countries
Intervention vs comparator	preferred and/or actual place of death/care
Primary outcomes	**Place of death**

	• Most deaths occurred in hospital with home as preferred place of care/death. • Home deaths ranged from 12% (Sweden) to 81,7% (Taiwan), 7 studies less than 25%, 10 studies 25-50% (including Belgium), 5 studies >50% • Less than 10% of rural deaths occurred in nursing/care homes or hospices; however, these options, especially hospices, were often not mentioned or not available. • The highest rates of home deaths were seen in cancer patients (53%- 81%) **Urban vs rural** • Rural patients are more likely to die in hospital or long-term care facility (in 4 studies) whereas other studies reported the change of dying at home to be greater in rural than urban locations. • The factors influencing the decision to transfer from home: proximity to a hospital or hospice, inability of carer to continue, increasing symptom burden, brief interval from diagnosis to death and patient choice. Two rural studies reported that the involvement of community nurses increased the likelihood of remaining home. **Preference for dying at home** • more than 50% of rural participants expressed a preference for dying at home. • preferences for home were greater in rural than urban areas. • qualitative studies: ○ home was the PPOD 'surrounded by family, and friends' and in the case of Indigenous Australians 'connected to land and family.' ○ Decision-making is complex and 'wishes' and 'preferences' are not necessarily the same. While wishing to remain at home, the participants in one study were aware that achieving this may not be possible due to 'concern about their carer and not wanting to become a burden', and so hospital became their preference. **Preference for hospital** • The preference for hospital ranged from less than 4% to 32%. • Reasons for preferring hospital: perceptions of better professional care, relief of carer burden and symptom control, familiarity with hospitals • Hospitals were not always available within the community, and displacement from community to access the closest hospital was not always acceptable with some participants preferring to forgo symptom management to remain in their community. **Preference for hospice** • Preference for inpatient hospice care ranged from 1%, 17% to 21%. • inpatient hospices were not available in all locations, therefore requiring patients to travel outside their immediate community or were not offered as an option. **Preference for residential aged care facility** • preference ranged from 1.1% to 21%. • many rural locations did not have aged care facilities
Secondary outcomes	/

Authors' conclusion	Despite striking variations between and within countries, a significant number of rural residents die in hospital; however, in many locations, they have a greater chance of dying at home than city residents. The PPOD (and care) for most rural residents is home; however, home is not the first preference for all. For some, due to remoteness, there may not be a choice as there is no local alternative to home or the community hospital is underserviced. Rather than a desire to remain home for whatever reason it may be more an 'aversion to hospital.' While it is important to increase community services to support those who wish to stay at home, improvements in palliative care within community hospitals and residential aged care facilities should not be overlooked as these places are often substitute hospice and the only alternative to home
comments	Studies were heterogeneous regarding rural setting, participants, inclusion criteria and assessment

Yamout et al., Preferred place of death for patients with terminal illness: a literature review, 2022	
Type + number of included studies	Search between 2000 and April 2020, n= 22 included studies (surveys, semi-structured interviews, cohort studies, patients' case notes)
Type of participants (+ setting)	Patients with terminal illness, age 18 and above, no gender restrictions, studies from Australia, Scotland, USA, Denmark, Taiwan, Egypt, UK, Qatar, Korea, Japan, Hong Kong, Italy, The Netherlands
Intervention vs comparator	Preferred place of death and factors influencing their choice versus awareness of caregivers and HC professionals
Primary outcomes	**Factors associated with choosing home as preferred place of death** • In almost all studies: home as preferred place of death (according to one study: even if sufficient support was not available) • Significant (but also contradictory) demographic predictors associated with increased preference to die at home: being female, having a postsecondary education, having higher income but also younger age, male sex, better physical and poorer mental health. Other studies: rural areas, who lived with their spouse or family, lower education level, having a support system. • Assumption that home death is impossible because belief that it is difficult to be cared for and die at home at EOL, most common reason: they do not wish to be a burden on their family. • Awareness of HC professionals: ○ most GPs and community nurses were aware that large number of patients would prefer to die at home. ○ they were informed by patient themselves, a family member or significant relative, a specialist or some other person. • other predictors: ○ physician home visits increased likelihood of home death, while frequent hospital visits decreased the likelihood of home death (in home PC recipients) • studies in MENA region: home as preferred place of death whereas caregivers' preferred place of death was hospital. Factors associated: ability to complete basic needs, presence and strength of home care and family support. Qatar: low rate of death at home because unavailability of PC services.

	• Cultural factors: relatives have permission to make decisions for the older patients (affecting place of death), hospitalization when treatment is unbearable and/or when rapid deterioration of health (makes death at medical ward more plausible) **Factors associated with choosing hospital as preferred place of death.** • Patients receiving palliative chemotherapy were more likely to die in an ICU unit and less likely to die in their preferred place of death (1 study) • Hospital was second preference for place of death (in 3 studies) • Factors associated with preference (of patients) to die in hospital: o poorer performance status and availability of family caregivers due to employment o strong and trusting relationship with HC professionals (especially with cancer patients undergoing chemotherapy for a period) o concern of being a burden to others. Consideration of the demands that are associated with taking care at home led patients with advanced cancer to choose hospital instead of home as preferred place to die. o to prefer a safer setting that can provide the necessary care. • Factors associated with preference of family caregivers: o poorer performance status and non-referral to PC unit **Factors associated with choosing hospice/palliative care wards as preferred place of death** • Hospice, public nursing home, private nursing home and palliative care unit as third preferred place of death, but also contradictory results reported: less than 5% preferred to die in hospice versus majority of patients. At least one hospice stay or admission is determinant (70% of patients with hospice experience preferred hospice as place of death versus 20% for those who had never been to a hospice) • Cancer patients who received advance home care that matched standards of hospital care were significantly less likely to die in hospital than those who received conventional hospital care (1 study) • Factors associated with preference to die in hospice: older age, female, metropolitan sectors, being single, higher education and household income. **Factors associated with choosing nursing homes as preferred place of death** • Factors associated with public nursing homes: old age, living in rented house, not expecting their partner to care of them at EOL, awareness of lower cost associated with spending EOL there
Secondary outcomes	Considerations reported in discussion section: • No studies included on patient-family caregiver congruence: caregiver preference does not reflect patient's preference and can affect patient's choice as well if they are aware about caregiver's choice • Major considerations that influenced decision regarding place of death: quality of life, availability, and ability of family caregivers, concerns of being burden to others, nature of relationship with HC professionals and quality of healthcare (1 study, USA) • Thinking of wellbeing of their families seemed recurrent in most studies. • Patients with lack of social support: relationships with HC professionals more important and PC as source of comfort

	• Factors with greatest influence on actual place of death: vicinity to services, ability of caregivers to support patient trough to EOL, symptom management, social circumstances, perspective towards death, importance of preferred place of death, gender, age, financial status, tumour type • Caregivers ○ are more aware of patients preferred place of death when care is focused on comfort rather than on cure + cancer patients are more likely to discuss with their caregivers compared to non-cancer patients. ○ are more likely to refer cancer patients to palliative care. ○ awareness of patients' preference was more often when care was psychologically and spiritually oriented. • cultural aspects: differences between collectivistic and individualistic cultures
Authors' conclusion	All studies have shown that most patients with terminal illness would choose **home** as their place of death. Palliative care should strongly advocate for the patients' preferred place of death to secure a better EOL care
Comments	

4 APPENDIX IV – EVIDENCE TABLES RELATED TO ACCEPTABILITY AND EFFICACY

Bainbridge et al., Common components of efficacious in-home end-of-life care programs: a review of systematic reviews, 2016[24]	
Type + number of included studies	N= 19 reviews, search 2003-2014
Type of participants (+ setting)	individuals in an advanced, palliative, or EOL stage of illness, in Europe, US, Israel, Australia, Japan
Intervention vs comparator	In-home EOL program vs in-home usual care Criteria of a program: • the intervention had to deliver palliative, hospice, or EOL care directly to individuals at home. • aim to support individuals to enable them to remain at home. • involve one or more health professionals who care for the individual at home
Primary outcomes	**Place of death** • The 40 studies reviewed showed significant improvements in six outcome domains: quality of life (n = 6/10), satisfaction with care (n = 9/12), performance status (n = 2/12), pain management (n = 11/16), other symptom management (n = 12/16), supporting home deaths (n = 8/12), and reductions in healthcare use or costs (n = 16/21) • all 12 most common components of efficacious EOL in-home programs had evidence that they improved outcomes in each of the six outcome domains examined. Three components were shown to have the most-consistent positive benefits on multiple outcomes: ○ linkage between community services on satisfaction (80%, n = 4/5 of programs had a positive effect), pain management (89%, n = 8/9), and place of death (83%, n = 5/6). ○ contact established with primary physician on quality of life (80%, n = 4/5), other symptom management (86%, n = 6/7), and place of death (83%, n = 5/6). ○ physician home visits on satisfaction (83%, n = 5/6), pain management (89%, n = 6/7), and healthcare costs or usage (88%, n = 7/8). **Costs** • Of the 17 studies that examined the cost benefit of the program, four RCTs and five non-RCTs reported significantly lower cost than usual care. Five studies reported that the program reduced costs but did not provide a test of significance for this finding. • For the nine programs (30% of total) found to significantly reduce costs, the most frequently reported components (present in 6 programs) were on call around the clock, around-the-clock home visits available, customized care plan driven by individual needs, and linkage with hospital.
Secondary outcomes	**EOL programs:** • Hospital-based outreach teams and community-based interventions were represented among the programs included in the review. Many of the programs were based on a core team that almost always included nurses and usually physicians, as well as allied healthcare professionals (e.g., social workers) and, in some cases, volunteers. Other models consisted of a nurse coordinator who monitored need and acted as a conduit between the individuals and community services as required. • Critical components of efficacious EOL in-home programs

Table 2. Summary of Critical Components of Efficacious End-of-Life (EOL) In-Home Programs

Intervention Element	Interventions Indicated, n (%) (n = 30)
Linkage[a] with hospital	20 (66.7)
Multidisciplinary team	20 (66.7)
End-of-life care expertise or training	19 (63.3)
Holistic care	18 (60.0)
Pain and symptom management	18 (60.0)
Professional psychosocial support	18 (60.0)
Linkage[a] between community services	17 (56.7)
Team contact on-call around the clock	15 (50.0)
Around-the-clock home visits available	14 (46.7)
Contact established with primary care or attending physician	14 (46.7)
Ongoing assessment	14 (46.7)
Physician home visits	14 (46.7)
Customized care plan or needs-driven care mandate	12 (40.0)
Case management or nurse navigation	11 (36.7)
Patient and family education	11 (36.7)
Physician available around the clock	11 (36.7)
Team case rounds	11 (36.7)
Individual-directed care or joint decision-making	10 (33.3)
Practical support	10 (33.3)
Bereavement support	9 (30.0)
Expert consultation with other providers	8 (26.7)
Spiritual support	8 (26.7)
Visiting volunteer services	8 (26.7)
Medical intervention	7 (23.3)
Advance care planning	5 (16.7)
Linkage[a] with residential hospice	5 (16.7)
Access to dedicated inpatient beds	4 (13.3)
One contact number	3 (10.0)
Chart in the home	1 (3.3)
Emergency response plan	1 (3.3)

[a]Linkage refers to open communication between the "team" providers and those in other settings to facilitate transitions and access to additional resources.

Source: retrieved from Bainbridge et al. 2016

- On average, each invention contained 11 components, with a maximum of 22. The 30 components were grouped into five categories: types of services offered, availability, characteristics of the care model, linkages to other resources, and process interventions. Seventy percent (21/ 30) of programs described at least one component from four of the five categories.
- The six most common components were that the program professionals had linkage with acute care, were multidisciplinary, had EOL expertise and training, provided holistic care (whole-person care that considered physical, emotional, and spiritual needs), provided pain and symptom management, and provided professional psychosocial support. Many programs also had linkages with existing community services, provided around-the-clock on-call for telephone contact and home visits, were linked to the individual's primary care, or attending physician, included ongoing assessment of the individual's condition, and involved physicians who made home visits.

Authors' conclusion (+ discussion)	In the programs examined, the most-common components were linkages with hospital and community services, a multidisciplinary team and holistic care model, and access to EOL care expertise and training, including expertise in pain and symptom management. These common components had clear pathways to improved outcomes.

	• First, linkages with acute care and community, formal or informal associations and channels of communication, help reduce the relational and bureaucratic barriers that service silos impose. This helps to increase interagency accountability and information transfer and to facilitate seamless transitions across settings. • Second, care that is multidisciplinary and holistic is more capable of meeting the diverse and individual needs of individuals at the end of life and their families, which often extend beyond the scope of medical interventions and include psychosocial and spiritual aspects. • Finally, professionals with EOL expertise and symptom management training know what to expect as the individual declines, how to prevent symptom exacerbations, how best to resolve these crises when they occur, and how to broach sensitive EOL discussions with individuals and caregivers. • It is likely that these components, and the others identified in the review, work synergistically to improve quality of life, satisfaction, and symptom management and ultimately to support individuals in dying at home and avoiding unnecessary late-life hospital use.
Comments	/

Bennardi et al., Palliative care utilization in oncology and hemato-oncolgy: a systematic review of cognitive barriers and facilitators from the perspective of healthcare professionals, adult patients, and their families, 2020[52]	
Type + number of included studies	Qualitative studies (n=33), quantitative studies (cross sectional, n=13) or mixed methods (n=6), search up to 2019
Type of participants (+ setting)	Healthcare professionals, adult patients with cancer and families, USA, Oceania, Europe, Asia, South America
Intervention (vs comparator)	Cognitive barriers related to PC utilization, access, provision, implementation, and integration
Primary outcomes	**Barriers and facilitators related to the relationship between healthcare professionals and patients** • Collaboration and communication between healthcare professionals and patients and/or their families *Barriers* ○ Difficulties in negotiating the transition to PC (chaotic and frequently occurred a short time prior death) due to lack of open communication between HPs and patients/families, lack of information on patient prognosis or available support and services. ○ Long term relationships between haemato-oncologists and patients may result in difficulty conducting EOL discussions. ○ PC use: receiving conflicting information on goals of care by HPs, lack of shared perspectives on patient conditions by HPs, no discussions on EOL between patient/family and oncologists, no preparation of patient/family to imminent deterioration of patient conditions, lack of effective communication and collaboration between HPs and patients/families, not using communication tools. ○ Lack of open communication due to absence of training in communication skills, problems with communication of bad prognosis, lack of communication skills, difficulty discussing spiritual, psychosocial, and emotional issues

	○ Patients/families: unwillingness of families to openly communicate with patient about diagnosis and prognosis, language or cultural barriers, family emotional reactions, difficulty in dealing with these for HPs, patient with impaired communication ability. **Barriers and facilitators related to patients and their families** • Awareness of palliative care *Barriers* ○ Lack of knowledge about PC, PC services and local services ○ Low awareness about PC ○ PC use: Uncertainty about PC scope, difficulty in defining PC, lack of patient education, lack of guidelines for patient education + lack of information on hospital and home services and difficulty in navigating the home PC system among patients. *Facilitators* ○ PC use: patient education, including increased knowledge of PC benefits and demonstration of PC utility via exposure, provision of clear information on EOL, integration of a lay health coach into oncology teams. • Emotions involved in cancer care pathways. *Barriers* ○ Early identification of PC needs + pc referrals: emotions and psychological reactions experienced by patients/families. ○ PC use: feelings of frustration and anger due to unpreparedness of family to patient transition to PC, fear of PC, resistance, or denial to accept actual medical condition and/or PC options. *Facilitators* ○ PC utilization: assessing the psychological condition, in particular patients' emotions. • Attitudes and beliefs towards palliative care *Barriers* ○ Family/patient reluctance, willingness to continue active treatment, negative view of PC, misconception about PC, PC being viewed as terminal care, beliefs about losing hope, differing perspectives about hope (overoptimism vs hopelessness) ○ Wish to receive care from family physicians or nurses rather than from unknown HPs in a palliative care unit. ○ Perception that PC is a lesser care option which must not be brought up at diagnosis or prognosis discussions. ○ Patient/family attitudes: infinite trust and faith in medicine, family forbidding discussion of PC during conversations about diagnosis or prognosis *Facilitators* ○ Early identification of PC needs: patients (openness to their own needs
Secondary outcomes	**Barriers and facilitators related to healthcare professionals** • Awareness of palliative care *Barriers:* ○ HPs' lack of knowledge of PC in general, or one or more areas pertaining it ○ Lack of understanding of PC services, their scope, or their applicability

- Lack of knowledge of locally available pc services
- Lack of education in PC, lack of practical training or working experience in pc

Facilitators

- Provision of education on PC, including education on the initiation phase, improved utilization
- Use of specific tools for PC needs assessment to address those needs in a timely manner.
- Previous experience, general knowledge of EOL care, PC education provision for HPs and clinical guidelines on PC delivery, led to greater utilization of PC services.

- Collaboration and communication between healthcare professionals

Barriers resulting in poor communication

- Poor information exchange
- Lack of effective team communication (e.g., on prognosis between PC specialists and oncologists)
- Lack of clarity and consensus on palliative care initiation
- Lack of opportunity of conversations between cancer care and palliative care professionals + lack of trusted relationships between professionals

Facilitators

- Improving collaboration between oncologists and PC team
- Involving other HPs (e.g. nurses) in the negotiation phase with patients and their family
- Joining other HPs at multidisciplinary meetings
- Improvement of strategic and unintentional visibility of PC teams in hospitals
- Active marketing of the utility of PC consultations
- Education about the expertise of PC team to nonpalliative professionals

- Emotions involved in cancer care pathways.

Barriers

- Issues with managing emotions in discussion of diagnosis, prognosis, and PC options (reported by HPs in oncological and haemato-oncological settings): emotional discomfort with death and dying, discomfort preceded by a feeling of failure and defeat, difficulty in managing the close emotional bond of patients or family members (sometimes resulting in personal identification with the patient), difficulty in addressing their reactions to prognosis disclosure.
- A lack of available psychological support for HPs who experience a high emotional involvement.

Facilitators

- Narrative-based training for HPs (in particular for nurses): to properly process emotions during discussions and to help building therapeutic alliances with patients and colleagues and to improve communication skills.

- Attitudes and beliefs towards palliative care

Barriers (common beliefs)

- Misbeliefs related to PC: Association of PC or hospice with death, inappropriateness of PC for complex problems if physical problems were not present, only PC goal being symptom management.
- Misbeliefs related to PC and cancer therapy: incompatibility of PC and cancer therapy, the development of PC services specifically for solid tumour cancer rather than for blood cancer.

	○ Misbeliefs related to cancer patients: suitability of PC for certain types of cancer, suitability for older patients, inappropriateness of PC for onco-hematologic patients. ○ Attitudes of HPs: talking about PC at an early stage not appropriate due to large amount of other issues to address, perceived PC as EOL care, preferred to maintain control also on PC, lack of trust in others professionals' oncology knowledge, difficulty of accepting death and avoiding discussing death, felt compelled to fully exhaust disease-directed treatment options prior to referring patients to PC professionals, source of confusion over roles which is increasing care fragmentation and threat PC patient autonomy, beliefs about losing patient care management, unconsciously avoiding admitting failure, personal crusades for the disease, cure-focused attitudes and over-emphasis on the treatment, PC incompatibility with the hospital life-saving culture, considering PC referring as the last resort, negative view of PC team involvement, past negative experiences, felt capable of providing PC without the involvement of PC team, hesitant about specific medications for pain/symptom management prescribed by the PC team, beliefs that patients or family might have inappropriate reactions to referral, discussions or referral upset patients and families, lack of interest in PC *Facilitators* ○ Attitudes in which the hospital team pays attention to ethical differences and acts according to patients' values
Authors' conclusion (discussion)	Curative model: cure-focused cultural aspects in healthcare settings may constitute a barrier to PC provision and referral + may explain the incorrect belief about PC as mostly conceived only to address physical symptoms + may influence the HPs 'perception and confidence towards PC and its' team's holistic approach + dealing with emotions and discussing spiritual issues may be very challenging. Suggestions made by the authors: • Training to increase collaboration and communication skills in PC settings should be available to HPs. • Implementation of the use of relevant tools for disclosing unfavourable information + guidelines and recommendations for how doctors should prepare to deliver bad news. • Triggers for referral to PC services should be activated when transitions in care are verified (e.g., metastases discovered) or by the emergence of distress recognized with specific screening tools. • Interprofessional collaboration skills should be enhanced. • Strategies to encourage collaboration between oncologists and PC team, to define a clear division or responsibility, and to encourage sharing of expertise of nonphysician PC team members should be applied to improve interface between oncologists and PC professionals.
Comments	No clear distinction between PC and HC. Barriers defined as: actual or perceived factors such as a perception or belief that make it difficult or impossible for patients to access PC. Facilitators defined as: actual or perceived factors as a perception or belief that make it easier or more likely for patients to access PC

Bone et al., Factors associated with older people's emergency department attendance towards the end of life: a systematic review, 2019	
Type + number of included studies	N= 21 studies, search up to 2017
Type of participants (+ setting)	Variety of study populations, including nursing home residents, patients living in the community, cancer, and non-cancer patients (dementia and heart failure), in US, Europe and Australia
Intervention vs comparator	Factors associated with ED visits when providing palliative care services vs usual care
Primary outcomes	**Socio-demographic factors** • high strength evidence that men were more likely to attend ED than women in the last year of life. However, community-dwelling men with dementia were less likely to attend than women. • high strength evidence that Black, Asian, and Minority Ethnic people were more likely to attend ED (versus white ethnicity), with a stronger effect observed for Black ethnicity. • rurality increased the likelihood of ED attendance. • no association reported between education and income and ED attendance. • people living in the community with a partner were more likely to attend ED. **Service-related factors** • lower ED attendance in the palliative/ hospice care group • early referral reduced ED attendance: late hospice enrolment (<7 days before death) was associated with higher ED use compared to no hospice, while medium (8–179 days) and long length (>180 days) enrolment was associated with reduced ED use. • moderate strength of evidence for no effect of being in a care home on ED attendance • non-significant lower odds of attending the ED for patients with advance care planning (low strength evidence) • no relationship or significant reduction in ED attendance between out of hours access to hospice physician or advice line vs usual care **Illness-related factors** • cardiovascular disease and non-cancer diagnoses, depression among dementia patients: increased ED attendance • dementia, stroke and lung disease, arthritis or rheumatism, mental health: none found evidence of an association with ED attendance. • comorbidities: little evidence of association with ED • cognitive impairment: lower ED attendance

Secondary outcomes

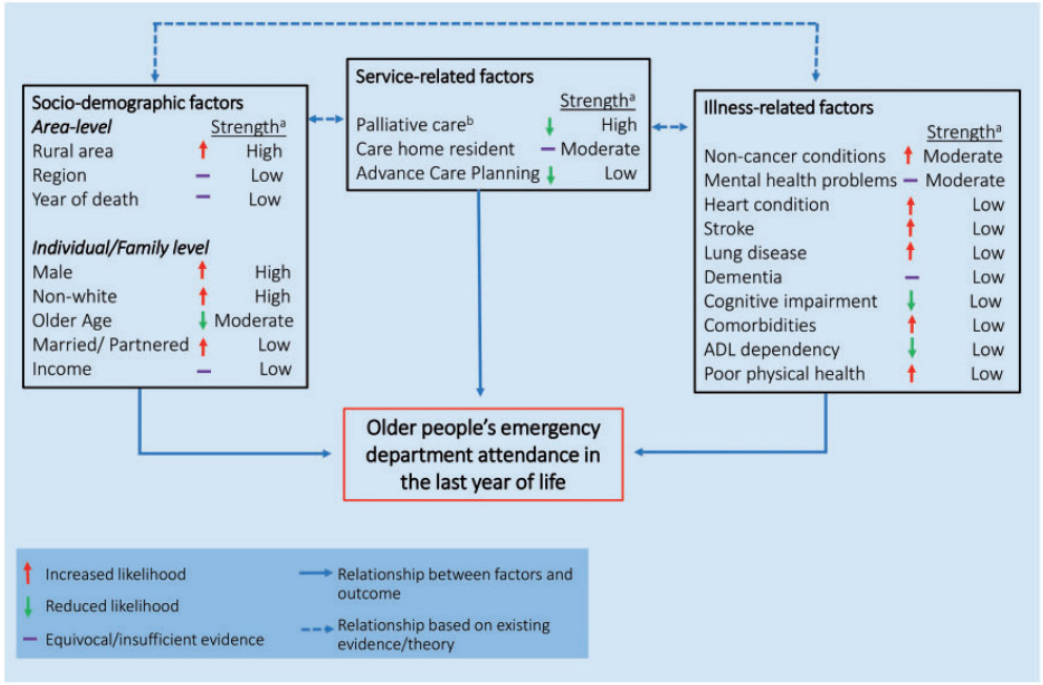


Figure 3 Model of factors related to emergency department attendance by people aged 65+ years in the last year of life. [a]Strength of evidence, graded according to algorithm; [b]palliative care includes specialist, generalist or hospice care; ADL=activities of daily living

Source: retrieved from Bone et al. 2019

Service-related factors include factors potentially amenable to modification by policy, commissioners, or practitioners. The socio-demographic factors represent area- or individual-level targets for services, while the illness-related factors are potential targets for intervention at a clinical level.

There is evidence that socio-demographic and illness factors are related to access to services. For example, older patients, ethnic minority patients and non-cancer primary diagnoses are each associated with lower access to specialist palliative care services. Similarly, there are well-established relationships between socio-demographic factors, particularly age and gender, and illness factors such as diagnoses and comorbidities.

Authors' conclusion (+ discussion)

We present the strongest evidence to date that provision of palliative or hospice care to older people is associated with lower ED attendance within the last year of life with mostly large effect sizes, and that earlier provision strengthens this relationship.

	These services may enable older people to remain in their usual place of care and reduce unplanned hospital ED attendance, in line with their preferences, by receiving timely care and treatment responsive to changing needs. There has been a recent move to include ED attendance as a quality indicator for end-of-life care. In North America, ED attendance is already included as a key measure of intensity of end-of-life care for cancer patients. However, whether high ED attendance is a cause or consequence of poor-quality care is untested. Qualitative research has found that cancer patients and informal caregivers perceive hospital as a place of safety and security during times of crisis and when care at home breaks down. There is limited investigation of the views of older people with non-cancer conditions on ED attendance towards the end of life, which is a key area for future research.
Comments	The authors grouped factors as (i) sociodemographic and pre-disposing factors (e.g. gender); (ii) illness-related and need factors (. e.g. diagnoses) and (iii) service-related and enabling factors (e.g. healthcare received).

Bowers et al., The end of life experiences of people living with socio-economic deprivation in the developed world: an integrative review, 2022[45]	
Type + number of included studies	Quantitative studies (n=34/40), qualitative studies (n=3/40) and mixed methods (n=3/40), search 2010-2020
Type of participants (+ setting)	Adult patients in the last year of life, with a diagnosis of terminal illness (malignant and non-malignant diagnoses), North America, Europe, Asia, Australia
Intervention (vs comparator)	The multidimensional EOL experience: perspective of the patient or the unpaid/family caregiver on end-of-life experiences, living with socio-economic deprivation (SED)
Primary outcomes	**Preferences and planning at EOL** • Preferences ○ Patients with higher educational level were more likely to choose supportive care: more likely to accurately know their prognosis, which was associated with preference for comfort-orientated and hospice-based care at EOL. • Future care planning (including designation of power of attorney, EOL discussions, completion of written instructions for care at EOL) ○ Higher household income increased odds of having a legally designated power of attorney for healthcare, but no impact on EOL discussions or written instructions. ○ Education level no impact on advanced care planning behaviour **Health and social care interactions at EOL** • Service use ○ Higher income or living in a neighbourhood with higher socioeconomic status: more likely to have inpatient hospice admissions. ○ Patients with financial strain (due to self-perceived poverty, disability, and high medication cost): more reliance on practical or social support (e.g., transportation, help with navigating insurance policies or benefits, food stamps) ○ Patients with higher levels of educational attainment: higher availability of informal caregivers + patients with highest socio-econ status: more unpaid caregiving hours provided (6h vs 2h in patients with lowest SES)

	○ Patients with SED: when accessed specialist palliative care services, more use thereafter (e.g., more follow-up visits with hospital PC service) ○ Patients with cancer: more likely to have GP face-to-face visits in last year of life if they had a lower income. • Treatment intensity ○ Patients with lower income, lower education level or no insurance: more likely to receive intensive treatment at EOL (including chemotherapy, attendance at emergency departments or >14 days hospitalisation prior to death, intensive care admission, use of mechanical ventilation and cardiopulmonary resuscitation) ○ + increased rate of transfer from home or nursing home to secondary care in the last month of life ○ Hospice care: having inpatient hospice admission during last 6 months of life reduced hospital admission by almost half but: patients with lower income and lower education less likely to utilise hospice. • Patient satisfaction ○ Limited and conflicting evidence: lower levels of education: higher satisfaction with care vs no association ○ Patients with reduced financial means and lack of private insurance: they meant they did not receive the same high-quality care. ○ Negative bias and stigmatization from healthcare professionals towards them die to their lower socioeconomic class and this impacted on perception of the care received. ○ More bad experiences or feeling their care needs were too complex, or even unidentified and unmet needs
Secondary outcomes	**Multidimensional symptom burden at EOL** • Physical symptoms: ○ lower income and education levels were generally associated with higher physical burden (pain) ○ poverty associated with increased receipt of medication for pain, dyspnoea, and emotional distress. • Psychological symptoms ○ Conflicting evidence on relationship between SED and psychological wellbeing: SED associated with lower functional, emotional, and spiritual wellbeing vs less anxiety and depression vs very low illness burden vs higher hopelessness and depression rate. ○ No consistent evidence regarding coping ability: higher education associated with better positive personal development and adjustment to trauma vs more likely to report feelings of having lost control, poorer coping with ADL activities. • Social and financial stress ○ SED associated with limited family support and heavy reliance on other sources of support but challenging access (difficult to navigate) ○ Financial distress common prior to diagnosis but worsened after, due to medical costs and inability to work (larger proportion of family income to health expenses, catastrophic health expenditure, higher health costs at EOL); feeling burdensome and useless; less likely to use (drug) reimbursement scheme
Authors' conclusion (+ in discussion)	• Following key findings were identified: Those living with SED have increased symptom burden; difficulty navigating complex healthcare systems at EOL and increased intensity of use once a link is established; a preference for (and more likely to have) intensive treatment at EOL; limited formal and informal social support; a greater propensity to experience financial distress and less participation in advanced care planning.

	• Call for proportionate universalism: system should be designed to incorporate needs of patients with SED, rather than needing them to adapt to a universal healthcare system, and for time and resources to be proportionate to level of disadvantage. • Financial benefits to not always reach those who need them most, leading to financial distress→ multidisciplinary and multi-agency approaches needed to support families to navigate health and social care and benefits system. • Patients with SED may have more interaction with health and social care professionals and thus potentially more opportunity to engage with future care planning, but this is not the actual experience
Comments	Review: a variety of different healthcare settings and systems in various countries, this may limit the generalisability across settings A lack of standard definition of SED

Buck et al., Hospital admissions and place of death of residents of care homes receiving specialist healthcare services: a systematic review without meta-analysis, 2022[11]	
Type + number of included studies	N= 92 studies (n=22 RCTS, n= 6 clinical controlled trials, n=16 cohort analytic studies, n= 30 cohort studies)), search 2020-2019
Type of participants (+ setting)	Older, long-term care home residents with or without dementia, in UK, USA, Australia
Intervention vs comparator	Specialist healthcare support designed to address the physical healthcare needs vs usual care. Characteristics of the initiatives: At least multidisciplinary teams (MDTs) delivered 46 initiatives. Nurses (often advanced/specialist practitioners) participated in at least 61 initiatives and physicians at least 49. Other disciplines included pharmacists, occupational therapists, physical therapists, dieticians, and emergency care practitioners. Most professional support was provided face to face. However, seven studies evaluated telemedicine services.
Primary outcomes	**Hospital admissions and ED transfers** • **N=75 studies, of which 11 studies in meta-analysis: overall no significant effect** ○ Studies to improve residents' general health (n=27): (significant) decrease in HA and ED transfers (strongest evidence with multidisciplinary support services, or nursing intervention with more emphasis on training; conflicting evidence in initiatives with involvement of nurses and (specialised) physicians) ○ Studies on acutely unwell residents (n=13): 11 studies reported decrease in HA and ED transfers, but no longer statistically significant after multiple testing ○ Studies on EOL care (n=11): no difference in HA and ED transfers ○ Studies aiming to improve prescribing (n=10): no difference in HA and ED transfers ○ Studies evaluating post-hospital discharge services (n=6): a decrease in HA and ED transfers, but no longer statistically significant after multiple testing ○ Studies with training on prevention (n=5): no difference in HA and ED transfers **Taxonomies of specialist home support:** • Assessment only (n=9 studies): no difference in HA and ED transfers

	• Assessment and management (with/without medical practitioners' involvement) (n=43 studies): decrease in HA and ED transfers • Training (n=14 studies): a decrease in HA and ED transfers, but no longer statistically significant after multiple testing
Secondary outcomes	Healthcare expenditure • Two studies on cost-effectiveness showed no significant effect on hospital admissions. • 5 studies with significant effects on transfers/admissions, provided cost data and reported cost savings, due to reduced admission and ambulance transfer frequency, hospitalizations
Authors' conclusion (+ discussion)	Evidence (albeit not definitive) was found for interventions addressing residents' general health needs, assessment and management services and non-training initiatives involving medical staff. Promising evidence was also found for services targeting residents at imminent risk of hospital entry or posthospital discharge and training-only initiatives. However, sensitivity analysis (correcting for multiple testing) suggested these results should be treated with caution. Similarly, although evidence was found for the ability of end-of-life services to enable residents to remain in the care home at end of life, the quality of the individual studies that explored this was generally weak, undermining confidence in the results. Stronger evidence was found for services undertaking assessment and management than assessment alone, demonstrating the importance of specialist healthcare services diagnosing and treating the healthcare needs of care home residents in partnership with care home staff.
Comments	Classification of services by service models • Assessment, no medical practitioner involvement: Provide assessment only. Advice and/or direct training may be given to care home staff and/or recommendations made to residents' primary care physicians. No on-going management or support of individual care home residents or additional input from physicians (over usual care). • Assessment, medical practitioner involvement: Assessment only as above, but additional input from physicians (over usual care) • Assessment and management, no medical practitioner's involvement: Provides assessment and on-going management of the health/care of residents (potentially including prescribing). No additional input from physicians (over usual care). Advice and/or direct training may be given to care home staff. • Assessment and management, medical practitioner involvement: Assessment and management as above, including additional input from physicians (over usual care). • Training and support: Support provided to the home, not individual residents. This may include training for care home staff and/or assistance with quality improvement initiatives. However, the team do not assess or see individual residents.

Carmont et al., Systematic review of the effectiveness, barriers, and facilitators to general practitioner engagement with specialist secondary services in integrated palliative care, 2018[35]	
Type + number of included studies	N= 17 studies, search up to 2014
Type of participants (+ setting)	adults (aged 18 years or older) receiving services through their GP, specialist hospital services or an integrated model of care
Intervention vs comparator	interventions designed to engage GPs and specialist secondary services in integrated palliative care vs standard or usual care (primary care only, secondary care services only or a non-integrated approach to care) GP engagement was defined as any organised cooperation between the GP and specialist secondary services in the care of the patient including shared consultations, case conferences that involved at least both the GP and the specialist clinician and/or other secondary services, and/or any formal shared care arrangements between the GP and specialist services. The specialist secondary service is either a specialist palliative service or a service providing specialist care to a palliative population
Primary outcomes	**Hospital use** - A significant decrease in hospital admissions and reduction of length of stay: case conferences and shared care - No difference between groups for time to death or readmission: intervention group had significantly fewer admissions each and fewer bed days per year (n=1 study) - Decrease in ED admissions and hospital admissions, decrease in length of day (n= 1 cohort study)
Secondary outcomes	**Intervention characteristics:** - All studies involved engagement of general practice with specialist secondary services in the provision of care to palliative patients. Twelve studies were based in metropolitan areas, and five studies included rural areas. - Specialist secondary services were palliative care services, a heart failure clinic, a heart failure and lung health service and a respiratory service. - Patients were diagnosed with a primary disease including cancer, cardiovascular disease, heart failure, respiratory disease, and renal failure, and one study included dementia and neurological disease. - Interventions included shared care, case conferences, home visits to the patient with both the specialist team and the GP attending and the use of a good practice framework (the Gold Standards Framework). **Facilitators to engagement of GPs with specialist secondary services in integration of PC** - Effective communication: o timely with an appropriate level of detail o patient information electronically o communication should occur with the most relevant people involved. - clear role definition: o roles should be clearly defined and understood by all involved. - availability of the GP o accessible through prompt appointments and telephone contact for medical care and referral o can provide emotional and family support. - family expectation that the GP will be involved.

	- the process should be organised and initiated by the specialist secondary service. **Barriers to GP engagement with specialist secondary services in integration of PC** - health system barriers: financial constraints for the GP and the hospital, workload, lack of standardised documents and systems, bureaucratic procedures, professional silos, lack of services and lack of infrastructure - communication barriers: poor communication creating personal issues (trust, poor relationships) between relatives and patients, lack of patient or family understanding of discussions with healthcare professionals, the quality of the relationship between the patient and the professionals, and a sometimes competitive or combative relationship between health professionals. - process barriers: roles within integrated care not being clearly defined, barriers to sharing information, health professionals' perceived lack of time, ambiguity around who should be involved, and communication and technology issues. - engagement barriers: a lack of clarity of purpose (e.g., future planning, acute medical issue), and participants being unprepared, either with not receiving information, or not reading the information prior to the meeting - other barriers: late referral, lack of understanding of patient prognosis by family, as well as medical professionals underestimating the seriousness of the patient's condition and therefore overestimating prognosis. **Some process and principles to facilitate GP engagement:** - communication is required providing an equitable status, or an equal respect and authority between all participants. - patients at risk of dying need to be deliberately identified: providing a systematic method of screening patient for palliative needs, and in addition a structure or framework of patient pathways (including referral pathways, provision of care after hours, primary contact details and management plans) - professional development: training improving knowledge and confidence for the care professionals
Authors' conclusion (+ discussion)	The review found evidence that engaging GPs in palliative care with relevant specialised secondary services is effective and provides positive outcomes for the hospital (reduced readmissions, shortened length of stay) and for the patient (pain management, symptom control, functional status). Interventions that used case conferences between specialist secondary services and GPs were effective in reducing hospital admissions and reducing length of stay as well as improving functional status. Specialist secondary services in these case conferences included a palliative service and a heart failure and lung health service. Shared care provided by a heart failure management clinic and GPs provided similar results. Additionally, conferences between specialist secondary palliative services and GPs at the patient's home improved pain control and symptomatology. Integration of GPs and specialist services serving palliative patients are effective.
Comments	/

Carpenter et al., A systematic review of nursing home palliative care interventions: characteristics and outcomes, 2020[12]	
Type + number of included studies	N= 13 (n=5 parallel group design, n= 7 quasi-experimental designs, n= 1 randomized partial cross over design), search up to 2019
Type of participants (+ setting)	Residents in nursing homes with or without dementia, and /or their family caregivers, US
Intervention vs comparator	Multicomponent nursing home palliative care intervention vs usual care or active comparator Definition of multiple component interventions: clearly integrating more than one palliative care domain
Primary outcomes	**Changes in clinical practice and healthcare use** • Positive changes in nursing home palliative care practices (n=6 studies): greater physician involvement in residents' care during the last week of life (n=2), increased use of a pathway to assist staff in providing EOL treatments in nursing homes (n=2), more discussion about hospice and higher hospice referral and enrolment rates (n=2) • Residents' acute care outcomes: reduced ED visits, rehospitalization, acute care admissions, days in acute care and in-hospital death (n=5). However: no significant effect on ED use in last three months of life, rehospitalization, in-hospital death (n=4) • Conflicting evidence on home death and hospice use (n=2): after PC consult intervention more likely to die in NH vs ACP not associated with greater likelihood of dying in NH or death while receiving hospice services **Advance care planning** • Conflicting evidence found increase vs no change in documented discussions of residents' EOL treatment preferences, DNR orders and presence of advance directives. **Costs/expenditures** • In 1 study: after staff education and training and clinical algorithm to identify residents at high risk of unmet PC needs: lower mean cost per resident at three months prior to death, also in final month of life
Secondary outcomes	Composition of multicomponent interventions, based on 8 National Consensus Project domains. • All studies incorporated 'structure and process of care'; n= 9 'ethical and legal aspects of care', and 'physical aspects of care', n=6 'care at the end of life', n= 4 'psychological and psychiatric aspects of care', n= 1 'spiritual, religious, existential aspects of care', none of the studies addressed 'cultural aspects of care' • Three major strategies: advance care planning, staff education (e.g. general concepts taught in a class or seminar) or training (e.g. mentoring palliative care skills in practice) and integrating a palliative care team. • Most common strategy: staff education and/or training, including audit and feedback strategy (shared results of bereaved family care evaluations with staff), staff champions or facilitators (to act as PC resources), staff training in EOL care alongside facility-based PC teams or consultative teams. • **Interdisciplinary palliative care team**: multiple disciplines (medicine, nursing, chaplains, social worker, and/or psychologist), either creating palliative care teams from existing nursing homes staff or implementation of consultation services • **Advance care planning**: ACP strategies most often screened for individuals that would benefit from an ACP conversation (e.g. illness prognosis and acute changes in clinical status, resident, and surrogate interviews)

	Patient-related outcomes • Pain assessment and management: after staff education (in one study in conjunction with facility-based PC team) improvement in pain and symptom assessment and management (nonpharmacologic treatments) • Pain and symptom ratings: no improvement found on pain ratings; conflicting evidence found on non-pain ratings (shortness of breath, depressive symptoms) • QoL: no effect in 3 months prior to death for residents with advanced dementia. However: better QoL ratings associated with higher staff knowledge and confidence providing PC **Family evaluation of care** • Conflicting evidence: higher bereaved family ratings of EOL care (associated with greater number of days receiving hospice services (1 study on residents without dementia) vs no significant improvement in family members' satisfaction with EOL care (in 2 studies on residents with dementia)
Authors' conclusion (+ discussion)	In six trials, interventions enhanced nursing home palliative care processes including increased use of care pathways, higher hospice referrals, and better documentation of pain and symptom assessment and management. However, in most trials there was mixed or insufficient evidence about the effect of palliative care interventions on reducing potentially burdensome care, resident/surrogate symptom ratings, advance care planning discussions and documentation, and improving family members' evaluation of care. Our findings suggest there is limited evidence that palliative care interventions improve nursing home end-of-life care outcomes. The design of palliative care teams differed across six studies, with some creating an internal team from the preexisting facility staff and others creating a consultative palliative care team; neither model demonstrated consistently positive results.
Comments	Limited evidence due to complexity of PC interventions: lack of effect on outcomes may reflect intervention implementation failure rather than ineffectiveness + difficult to assess what parts of each intervention were most effective and what parts did not provide benefit.

Chan et al. , End-of-life care pathways for improving outcomes in caring for the dying, 2016[28]	
Type + number of included studies	Cochrane review, n= 1 RCT, search up to 2015
Type of participants (+ setting)	?
Intervention vs comparator	End-of-life care pathways vs usual care (no pathway) or vs care guided by another EOL care pathway across all healthcare settings (e.g. hospitals, residential aged care facilities, community)
Primary outcomes	The study, a cluster RCT of 16 hospital wards, compared the (Italian version of the) Liverpool Care Pathway (LCP) with standard care. In analysis separate section on LCP history + withdrawal + modifications in other countries or for other populations/care settings (Chan[28], Husebo[29])
Secondary outcomes	/

Authors' conclusion (+ discussion)	Although strong evidence supporting end-of-life care pathways is lacking, the principles underpinning such pathways remain relevant. Plans for end-of-life care should be developed in open consultation with the patient and significant others. Without strong evidence supporting the effectiveness of the end-of-life care pathways, it is difficult to justify the implementation of an end-of-life care pathway given the resource intensive nature of the intervention. It would be prudent to invest resources into other evidence-based strategies for improving the standards of end-of-life care. All health services using an end-of-life care pathway are encouraged to have their use of the pathway, to date, independently audited, with particular emphasis on the Neuberger's findings (Neuberger 2013). Any subsequent use should be based on carefully documented prospective evaluations.
Comments	/

DiMartino et al., Do Palliative Care Interventions Reduce Emergency Department Visits among Patients with Cancer at the End of Life? A Systematic Review, 2014[22]	
Type + number of included studies	N= 13 studies (n= 2 RCTs, n= 10 observational studies, n= 1 non-RCT/quasi-experimental study), search up to 2014
Type of participants (+ setting)	Patients with cancer at the end of life (adult patients with advanced cancer or metastatic disease), in USA, Spain, Canada, Australia
Intervention vs comparator	palliative care interventions implemented in the hospital, home, or outpatient clinic vs usual care
Primary outcomes	ED visits • US-based studies: ○ RCTs: no significant difference between usual care and early PC delivered by nurses using case management, educational approach (1 RCT) + no significant difference between regular oncologic care or early PC delivered by team of PC physicians and nurses (a nonsignificant trend in reduction of ED visits in patients who died) (1 RCT) ○ Observational studies (n=3): significant decrease of ED visits in study on hospice enrolment; patients who had died of cancer and remained in hospice until death less frequently visited ED compared to patients who had disenrolled from hospice; third study showed lower % of hospice patients with fewer than one ED visit in last month of life compared to nonhospice patients. However, in studies without Medicare analysis: no significant difference in fewer than one ED visit in last month of life in PC vs non-PC; non-significant lower incidence of fewer than one ED visit in patients who received timely PC services (>2 weeks before death); non-significant difference in ED visits in last month of life between PC and non-PC. ○ Non-RCT/quasi experimental study (n=1): no significant difference in number of patients experiencing fewer than one ED visit within 30 days of death between usual care and early palliative/supportive care program delivered by nurses, social workers, and spiritual care counsellors • Non-US-based studies ○ Observational studies: overall significant effect on reducing ED visits in patients who received palliative home care team services (2 studies); who received physicians PC assessments within 2 weeks of death (1 study); who received PC Integration Project (PCIP) (1 study); patients with no PC or late admission to PC more likely to visit and ED in 90 days before death (1 study)
Secondary outcomes	/

Authors' conclusion (+ discussion)	Evidence regarding whether palliative care interventions implemented in the hospital, home or outpatient clinic are more effective than usual care at reducing ED visits is not strongly substantiated based on the literature reviewed. Although some studies found a positive effect, the majority of these used either observational designs or were conducted outside the United States. There currently is little evidence to support which combination of palliative care components are most effective across a variety of settings in reducing ED visits, and more research with rigorous methods is warranted.
Comments	Definition of hospice care: patients are no longer being actively treated for cancer and are required to have a life expectancy of less than 6 months to receive benefits. Conceptual model: depicts a linear trajectory of care from screening to diagnosis, to treatment, to end-of-life, where failures in the types of care provided and during transitions between the types of care can occur, which ultimately impact patient outcomes

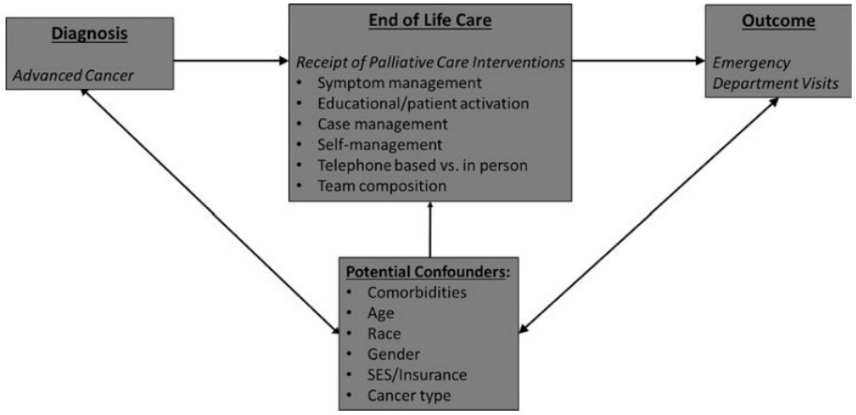


FIG. 1. Conceptual model. (Adapted from Zapka et al.[13])

Source: retrieved from DiMartino et al., 2014

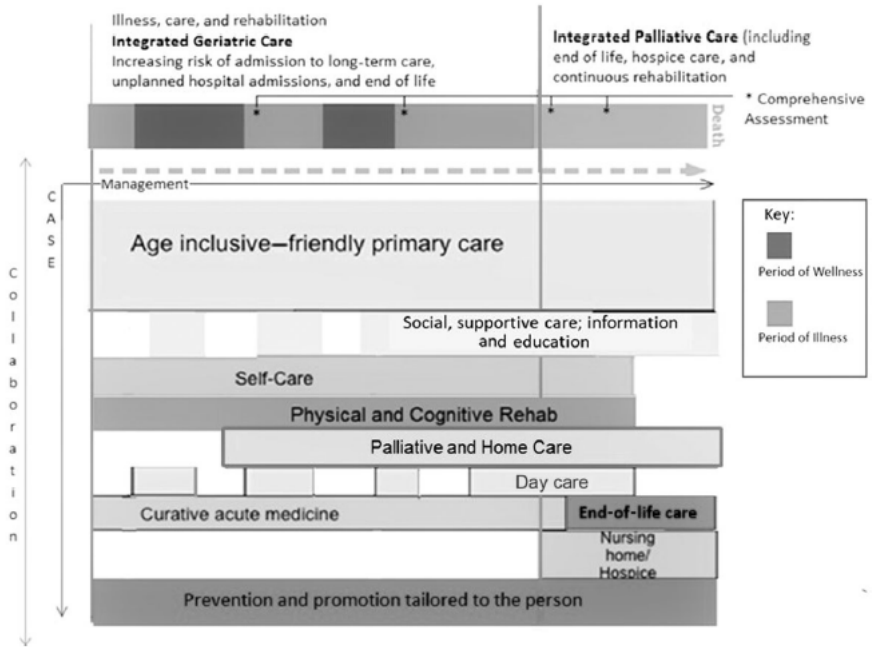
Engbers et al., Informal caregivers' perception of needs from hospice professionals: an integrative review, 2019[56]	
Type + number of included studies	Qualitative studies (n=12), search 2013-2018
Type of participants (+ setting)	Informal caregivers of home hospice patients, US, England, Ireland, Taiwan
Intervention (vs comparator)	Perceptions of informal caregivers (ICs) regarding their experiences with hospice professionals (formal services) (beneficial contributions of hospice professionals)
Primary outcomes	**Providing easy access to desired care** • Importance of easy access: need for prompt symptom management for the patient, necessity of frequent reassessments due to changing nature of the patient, the security of having HC professionals available 24h a day and ease of having hospice provider be the point of contact for any health-care question, providing respite care, performing tasks during their visits to ease the caregiving burden, suggesting appropriate durable medical equipment. • Emotional benefits of working with HC professionals: becoming confident caregivers and forming a relationship with HC professionals • Missed opportunities: not aware of all the services offered by hospice, HC professionals should be more direct and assertive when offering services, uncertainty whether they had access to hospital if needed, need for better explanation of roles of different HC professionals, access to more minority HC professionals. **Building up the caregiver (empowerment)** • Need for training: education on when and what to expect at time of death, individualized based on IC specific abilities and patient's needs, receiving information in small amounts and teaching while doing, to be encouraged to ask questions. • Need for encouragement and reassurance on IC role. • Need to be acknowledged by HC professionals: wanting to remain primary caregivers, treated with respect, have their opinions valued. **Forming a relationship** • Importance of continuity of care: trust and relationship with HC professionals is necessary to relinquish care for their loved ones to hospice provider, important relationship during period of isolation, HC professionals conserved as friends/family. • After death: need for closure with HC professionals. **Utilizing culturally relevant interpersonal skills** • Direct and honest communication (finding balance between being direct and sensitive): promoted trust in HC provider and helped IC feel more prepared, importance of HC professionals to guide difficult discussion with sensitivity. • Cultural relevance in interpersonal skills: giving a change to ask questions away from the patient, expectation of best interpersonal skills from HC professionals (empathic, kind, remaining calm in midst of emotional and distressing situations, listening, expert skills in sensing needs of IC and patient • Presence of HC professionals to be special and reassuring
Secondary outcomes	/

Authors' conclusion (+ in discussion)	• Knowledge of available services: ICs need better descriptions of the available services and better explanations of why and how to use those HC services. • Adequate training: need for training from HC professionals concerning the skills needed to care for their loved one. • Acknowledgement of the IC as main caregiver Solutions suggested by the authors: • Use of instruments to measure ICs' knowledge of services and caregiving skills. • Including ICs in interdisciplinary team meetings • Recruitment of minority hospice professionals • National efforts to include minorities in hospice. • Enactment of policies that promote continuity of care and prioritize impact of relationship formation by HC professionals. • Initiating bereavement visits by current HC professionals
Comments	/

Evans et al., Service delivery models to maximize quality of life for older people at the end of life: a rapid review, 2019[27]	
Type + number of included studies	N= 72 reviews, search 2000-2017
Type of participants (+ setting)	Older people (>60 years) and at end of life (people described as being in the last one to two years of life, using a service typically accessed during an advanced stage of disease (e.g., specialist palliative care, nursing home) or having advanced disease, US, Europe, Western Pacific regions
Intervention vs comparator	Palliative care vs usual care
Primary outcomes	Two overarching classifications of service models identified, with common components such as person-centred care (focus on physical and psychosocial interventions), education (subdivided into its recipients: patients/caregiver with training on e.g. self-management; staff with training on PC by specialist PC teams) and workforce (workforce development programs to support EOL care in NH) • Integrated geriatric care (focus on physical function, concerned more in earlier stages of functional decline) • Integrated palliative care (focus on symptom severity and psychosocial/spiritual concerns during the advanced disease stage up to death): encompasses both specialised PC services provided by teams for patients with complex problems as well as generalist services from professionals with a basic knowledge of PC and treating patients with chronic progressive conditions. Three common methods for integration of care across services (and to manage continuum of care over time): • Comprehensive assessment: person-centred assessment of needs across physical, psychological, social, and spiritual domains. • Case management: Coordinating care for patients and their caregivers by assigning each case to an individual and/or a team.

	• Collaborative working: importance of multidisciplinary teams with main members nurses, physicians and social workers, physiotherapists also often included. Only in 5 reviews volunteers also involved in service delivery. Health service use and costs (narrative reporting, difficult to differentiate) • Case management: inconsistent findings with reviews reporting no effect on HC use, effective on admission to nursing homes only after high-intensity care (>9 visits), no effect on institutionalization and readmission. • Integrated geriatric care: effective on shorter hospital stay, discharge to a nursing home, discharge to home, readmission. (directions of effect not reported) No effect on length of stay. • Combination of integrated geriatric care and integrated palliative care: effective on all-cause hospitalization • Integrated palliative care: effective on dying at home, no effect on death not in nursing home
Secondary outcomes	Other outcomes reported in the review: quality of life, functional outcomes, dignified EoL care, survival
Authors' conclusion (+ discussion)	We argue that service use is best triggered by individual need and intention to live life as well as possible by maintaining physical and cognitive function and autonomy (functional and decision making) until the time of death. This marks a shift away from temporal indicators like prognostication. This integrated approach requires a paradigm shift in older age and EoL care from within (or even from) the alignment with prognostication, to allowing costing and service access based on perceived needs, individual goals, and intended outcomes. It is widely advocated that palliative care be delivered based on need and benefit, not diagnosis or prognosis. This places person-centred care at the core of care delivery and emphasizes a people-centred approach to health system design and delivery.
Comments	/

Figure 3. Range of Service Packages for Universal Health Coverage for Older People Nearing the End of Life



Modified from a WHO Kobe Center working framework (Ong and Evans 2014[132]).

Source: retrieved from Evans et al., 2019

Firth et al., How is community-based 'out-of-hours' care provided to patients with advanced illness near the end of life: a systematic review of care provision, 2023[15]	
Type + number of included studies	N= 64 (n= 38 quantitative studies including 6 RCTs, n= 14 qualitative studies, n= 4 mixed methods, n= 8 service development papers), mixed methods, search 1990-2022
Type of participants (+ setting)	Adults (over 18 years) with advanced illness from malignant or non-malignant disease in the last year of life or their family caregivers receiving out-of-hours palliative care intervention or service, in UK, Australia, Sweden, USA, the Netherlands
Intervention vs comparator	A palliative care intervention with out-of-hours care vs?
Primary outcomes	**Effectiveness** was reported in 8 RCTs or controlled cohort studies: • Most evidence of effectiveness reported for 24/7 specialist PC (combination of advisory and hands-on clinical care): conflicting evidence found but some tendency towards higher attainment of preferred place of death compared to non-users, less likely to die in hospital. • 24/7 specialist PC (advisory care only): lower symptom distress and better functioning for patients in intervention group however emergency department usage was equivalent. **Economic evaluation:** • Overall, poor quality of economic methodology • Mixed results for cost implications: lower hospital costs among people receiving home-based nursing care at EOL, no differences found between users and non-users of Hospice Rapid Response Service except higher costs near death among users. • Some potential cost-savings estimated when specialised PC service (free-of charge, round-the-clock, live-in support person) was provided
Secondary outcomes	15 categories of components of models of care, with three overarching dimensions (service time (if a service was provided during both daytime and out-of-hours or if it was only an out-of-hours service); focus of staff delivering the care (specialist palliative care/dedicated palliative care general palliative care or integrated specialist and general palliative care, type of care delivered (if it was advisory only and/or hands-on clinical care)) • 24/7 specialist PC (hands-on clinical care only): mainly for patients in last few days of life, mainly monodisciplinary by specialist palliative care nurses and/or health care assistants • 24/7 specialist PC (combination of advisory and hands-on clinical care): care delivered by nurses, access to a specialist PC medical doctor out-of-hours, some services specifically for patients in the dying phase, sense of security and high-quality coordination of services. • 24/7 specialist PC (advisory care only): available to all patients receiving PC and not limited to the dying phase, provided over the phone, with some also offering home visits, in one service access via tablet to hospice staff for patients at home, some services the ability to coordinate with other services to provide hands on care in the patient's home, delivered by registered nurses; sense of comfort for patients/families by always knowing care was available but integration and continuity were impeded with lack of access to shared patient records out of hours.

	• 24/7 Integrated specialist and general palliative care (hands-on clinical care only)): No eligible published papers found in the review. • 24/7 Integrated specialist and general palliative care (combination of advisory and hands-on clinical care): delivered by multidisciplinary teams, enables the services to provide numerous interventions to patients and families out-of-hours. • 24/7 Integrated specialist and general palliative care (advisory care only): (only 1 study) from an integrated multidisciplinary team (GP and hospice service), supports patients to die in their preferred place of death, no qualitative studies found. • 24/7 general palliative care (hands-on clinical care only): extended visits by care aids (healthcare assistants), including a sitting service, and personal and supportive care, monodisciplinary with care delivered by unregistered care aids with a specific focus on meeting activities of daily living, care aids were provided for patients who lived alone to support personal care. • 24/7 general palliative care (combination of advisory and hands-on clinical care): provided by generalist services and comprising multi-disciplinary teams, care reported as high quality and supportive but also concerns of not feeling listened to and out-of-hours family physicians being little informed about the patient. • 24/7 general palliative care (advisory care only): care coordination, a service led by family physicians providing out-of-hours care to patients registered with their practice. • Out-of-hours only – specialist PC (hands-on clinical care only): one, older study highlighted challenges of accessing to prescriptions for medication for symptom management out-of-hours. • Out-of-hours only – specialist PC (combination of advisory and hands-on clinical care): one study, a night sitting service which provided patients and families with both advisory and hands on clinical care by a multidisciplinary team and described demand outstripping supply by twice as many night care episodes requested than could be provided. • Out-of-hours only – specialist PC (advisory care only): provided by nurses, in three studies only telephone advice, in one study only for health care professionals, no other interventions other than advise. • (Out-of-hours only – general PC (hands-on clinical care only)): no eligible published papers found in review. • Out-of-hours only – general PC (combination of advisory and hands-on clinical care): provided by a generalist multidisciplinary team (in one study) • Out-of-hours only – general PC (advisory care only): provided by generalist out-of-hours services (in 8 of 10 studies GPs/family physicians), in 1 study only face to face, in remaining studies both telephone and face to face services; qualitative studies reported the importance of continuity of care, the preference of seeing own patients/family physicians, challenges both family physicians and patients faced in difficulty of accessing patients notes, reluctance of patients and families to contact out-of-hours services due to lack of continuity of care and needing to re-tell their story and feeling unknown, the importance of family physicians having easy access to specialist palliative care for advice was also highlighted.
Authors' conclusion (+ discussion)	All the studies reporting effectiveness reported provision of 24-h care provided by specialist palliative care, with the most evidence of effectiveness provided for category 2: where the services are provided 24/7 by specialist palliative care and can

	provide both hands on clinical care, alongside advisory care. Unfortunately, evidence from economic evaluations and service utilisation for out-of-hours services was inconclusive due to limited number of studies and poor quality. Three overarching dimensions: • **Service times:** 24/7 access to care for palliative patients has previously been reported as a component of home care that results in significant cost reduction. Our review reiterates the importance of 24/7 care for this population. Our qualitative synthesis has also highlighted the importance of patients and families feeling known to a service providing out-of-hours care. Shared patient records were deemed important, as were services giving consistent information to patients and families, and patients receiving responsive and appropriate care aligned with their priorities and preferences. • **Focus of staff delivering the care:** Although more research is specifically needed on effectiveness of the different categories of general palliative care identified in this review. A recent review has highlighted the importance of a capable workforce that works collaboratively across disciplinary boundaries, to provide comprehensive and ongoing multidimensional assessment. Further research is also needed on models of integrated working out-of-hours between specialist and general services for palliative care, to ensure care provided is well coordinated. • **Type of care delivered**: Most evidence on improved outcomes for patients was for category 2 services, which provided a combination of both hands-on clinical care and advisory care. This also echoes patients and families assertion for high quality coordinated care that meets their needs (whether this be advisory or hands on clinical care) and ensure sense of comfort and safety.
Comments	Definition of out-of-hours: A study of a palliative care intervention or service was included if community-based and included out-of-hours care, provided care outside hospital and other institutional settings as far as possible. Out-of-hours care could be described as one component of a model of care or the main component of the model of care. Provision included by primary or secondary care and by private, public, or voluntary sectors. There is no internationally recognised term used for 'out-of-hours' provision and is variably referred to as 'after hours', 'on call', 'outside of normal working hours' or 'weekend' care.

Flierman et al., Effectiveness of transmural team-based palliative care in prevention of hospitalizations in patient at the end of life: a systematic review and meta-analysis, 2023[18]	
Type + number of included studies	N= 19 studies (n= 7 RCTs or a cluster RCT, n=2 prospective non-randomized studies, n=1 prospective quasi-experimental study, n=4 retrospective before-after studies, n=1 clustered partially controlled before-after study), search up to 2021
Type of participants (+ setting)	Adult patients in need of palliative care,
Intervention vs comparator	interventions of team-based collaboration between primary and secondary care vs usual care or non-transmural palliative care
Primary outcomes	**Hospital admission** • Overall, the odds of hospital admission were significantly reduced (n=12 studies), however with considerable heterogeneity in the meta-analysis • Subgroup differences: Interventions with collaborative teams and hospital-based teams resulted in fewer hospital admissions, but this effect was not observed in case-management interventions.

	Place of death • More home deaths, with larger effect in hospital-based teams than in collaborative teams (however high heterogeneity between two subgroups) • Majority of patients in 1 study died at their preferred place of death (but no control number reported) **Mean number of admission days** • Conflicting evidence found with no significant difference vs lower mean number of admission days in intervention group
Secondary outcomes	**Three organisational models for the teams:** • Collaborative teams: These teams involve structural collaboration between professionals from both the hospital and community. They follow patients transitioning between care settings. They can provide medical care and symptom control at home. • Hospital-based teams: These teams provide care for patients in the hospital and community setting (through home visits), without structural collaboration with primary care professionals. These teams are mostly responsible for all care and can treat patients at home. • Case management: Case managers collaborate with hospital-based multidisciplinary teams. The focus is on advance care planning and not on providing treatment at home.
Authors' conclusion (+ discussion)	Meta-analysis demonstrated overall a lower number of patients with hospital admissions, and more home deaths. However, observing a precise effect estimate was impossible because of the heterogeneity. Subgroup analysis only partially explained the between-study variance but indicated hospital-based teams were the most effective.
Comments	Definition of transmural team-based palliative care: teams that provide continuous care for patients at the end of life while the patient moves between settings. Teams had to provide at least face-to-face consultations at home or in the hospital. We did not consider interventions to be transmural team based when teams were solely hospital based, for example, when they followed patients in the outpatient setting or were community/hospice based with referrals from the hospital but no further or unclear collaboration with the hospital.

Fulton et al., Integrated outpatient palliative care for patients with advanced cancer: a systematic review and meta-analysis, 2019[33]	
Type + number of included studies	N= 10 studies (RCTs), search up to 2018
Type of participants (+ setting)	adults with advanced cancer
Intervention vs comparator	interventions delivered in outpatient settings, evidence of integration between palliative care and oncology services vs usual oncology care
Primary outcomes	**Place of death** - Patients receiving PC were more likely to die at home (n=3 studies) than those receiving usual oncology care **Aggressiveness of care near the end of life (n=3 studies)**

	- One study conducted in patients with lung cancer reported a composite measure (chemotherapy 14days before death, no use of hospice care, or admission to hospice) - Three studies reported chemotherapy use at end of life, one of which showed an intervention effect (chemotherapy in the last 60days of life, 32/61 vs 47/67; p = 0.05). One study reported on the proportion of patients receiving chemotherapy at all, while the other reported receipt of chemotherapy in the last 60days of life; neither showed an intervention effect. **Healthcare utilization** (reported inconsistently across studies) - ED visits: modestly lower in intervention group (n=3 studies) - Hospitalizations: modestly lower in intervention group (n=3 studies) - ICU utilization: no difference found. - Costs of care: intervention was associated with a lower mean total cost per day throughout the study period (non-significant difference) - Chemotherapy costs in the last 30 days of life were significantly lower in intervention group (n= 1 study)
Secondary outcomes	Patient-related outcomes were also reported but not presented in this evidence table. Characteristics of the interventions: - Palliative care was delivered by a multidisciplinary team of two to five clinicians; all included nurses, five included a palliative care physician, three included a mental health professional, and two included chaplains. All studies provided services during outpatient visits; five also included telephone-based care, and three described delivery of written materials - All palliative care study interventions addressed physical and psychological symptoms. Most interventions also addressed social, spiritual, ethical, and legal, and end-of-life aspects of care. Structural issues (e.g. interdisciplinary team engagement with patients or families) were addressed explicitly in half the interventions, but cultural issues were not. - The intensity of services varied greatly, ranging from four sessions weekly to contacts every 2– 4weeks until death. - Of the 10 trials, 2 were classified as having basic collaboration on site and 4 as having close collaboration on site with some systems integration. Four studies could not be classified due to no response from authors. In all trials for which the authors responded, palliative services were physically or virtually co-located in the same facility as oncology services, although not necessarily the same space. Standard communication about treatment issues, interactive communication, and routine communication exchanges between palliative and oncology clinicians occurred in at least half the studies.
Authors' conclusion (+ discussion)	We found a pattern of positive effects, including improved survival and short-term quality of life. Strength of evidence was rated for quality of life, symptom burden, and mortality. Ratings were as follows: high strength of evidence for mortality, moderate strength of evidence for shorter term quality of life, low strength of evidence for longer term quality of life, and very low strength of evidence for symptom burden. Concerns that contributed to the lower strength of evidence were high risk of bias and imprecision that was attributed to the 95% CI not excluding a small and small-to-moderate effect. Effects on other outcomes such as healthcare utilization and caregiver outcomes are less studied and warrant further attention. In addition, gaps in evidence for some policy-relevant outcomes and critical intervention elements remain.

Comments	Healthcare organisations have described various integration methods, including co-rounding models for hospitalized patients, co-located outpatient services, and stand-alone services.

Gaertner, Effect of specialised palliative care services on quality of life in adults with advanced incurable illness in hospital, hospice, or community settings: systematic review and meta-analysis, 2017	
Type + number of included studies	N= 12 included studies (10 RCTs published in 12 articles), search up to 2016
Type of participants (+ setting)	Adult inpatients or outpatients treated in hospital, hospice, or community settings with any advanced illness (defined as malignant and non-malignant diseases that lead to a decline in general health and eventually to death)
Intervention vs comparator	Specialised palliative care (minimum requirement: multiprofessional team approach) in hospitals, hospices, or community settings versus standard care. Sub analyses: cancer vs non-cancer; different non-cancer diseases; early vs not early specialist palliative care (early defined as Eastern Cooperative Oncology Group 0-2 or Karnofsky index 50-100 or 6-24 months estimated survival or initiation of specialist PC within 8 weeks after diagnosis of an advanced incurable illness); younger vs elderly patients (age <60, 60-70, >70); inpatients vs outpatients specialist palliative care was defined as a “service of health care professionals from at least two different professions that provides or coordinates comprehensive care for patients, provided in hospitals, hospices, or community settings, at home
Primary outcomes	**Survival, place of death**: inconclusive results: 1 study reported a higher probability to die at home vs more deaths in hospitals in SPC group in other study **Cost of care (reported in 3 studies):** inconclusive results. • No difference between average mean costs per day and expenses for hospice care between SPC and standard care. However, in the same study, expenses for chemotherapy were significantly reduced for SPC versus standard care. • The mean health costs per patient were significantly lower for SPC versus standard care while hospitalization costs did not differ. • No differences were reported in the mean charge per patient for all medical centre services
Secondary outcomes	**Patients’ quality of life** (measured with a variety of validated assessment tools) • Specialist palliative care vs standard care: ○ Small significant effect in 3/8 studies, non-significant effect in 4/8 studies in favour of specialist palliative care ○ Meta-analysis: overall small significant effect in favour of specialist palliative care (SMD 0.16, 95% confidence interval 0.01 to 0.31; n=1218, six trials, I2=38%, moderate quality of evidence; 95% prediction interval −0.22 to 0.54) • Sub analyses. ○ Effect in favour of specialised PC marginally higher for patient with cancer, highest for early care. **Pain** • Small but non-significant effect (−0.38, 95% confidence interval −0.82 to 0.06; n=410, three studies, I2=23%).

	Distress and overall symptom burden; depression; anxiety; dyspnoea; social well-being; nausea, spiritual well-being; satisfaction with care; fatigue: inconclusive results **Characteristics of the interventions** - All trials were performed in hospitals and none in hospices or community settings. - Social workers and chaplains were part of the multiprofessional team in five of the 10 trials (50%); all 10 studies included a nurse, and nine studies (90%) included a physician. - All trials provided a "specialist palliative care for all" approach; none initiated integration of specialist palliative care according to the individual needs or symptoms of patients as identified through screening
Authors' conclusion (+ discussion)	Specialist PC and its early integration might have a small effect on the quality of life of patients with cancer and without cancer, based on moderate quality of evidence. The effects on QoL were most pronounced for patients with cancer and early integration of specialist PC. The results for pain and other outcomes were inconclusive. We strongly support such an approach ("general palliative care for all plus specialist palliative care as needed"). This model recognises the importance of general palliative care (and interventions that will strengthen palliative care) as well as the necessity to provide specialist care to patients for whom general palliative care is not enough. Yet, we must emphasise a missing link. In our view, this link is routine structured screening for needs of all patients for palliative care as reported by the patients themselves. Such routine screening (for example, for symptom burden) is known to increase quality of life in these patients and reduce emergency admissions and could be a practical trigger to identify those who need specialist palliative care.
Comments	Use of different tools in the included studies, which required a re-expression of the SMD on the EORTC QLQ-C30 global health/QoL scale. Large variation between studies (study population, outcomes, clinical setting, duration of the study), high risk of bias in most of the studies Potential overestimation of effects due to lack of blinding in specialist PC interventions, large number of missing values because of early death of patients,

Gomes et al., Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers, 2013[4]	
Type + number of included studies	N= 23 studies (n= 16 RCTs), search up to 2012, Cochrane review
Type of participants (+ setting)	adult patients with advanced illness and their family caregivers, in Canada, Italy, Norway, Sweden, UK, US
Intervention vs comparator	home palliative care services vs usual care Usual care: community care (primary or specialist care at home and in nursing homes), hospital care (inpatient and outpatient) and in some instances palliative or hospice care (or both)
Primary outcomes	**Place of death** • Meta-analysis showed increased odds of dying at home (n= 7 trials) **Cost** • Evidence on cost-effectiveness (six studies) is inconclusive.

	ED and ICU visits • There was moderate evidence of no statistically significant effect on ED visits (six RCTs) and on intensive care use (two RCTs). Four of the six RCTs that examined the effect on ED visits found no statistically significant differences between intervention and control groups. In addition, a sub-analysis of the last two weeks of life for the 33 patients that died in Zimmer 1985 found there were no ED visits in either group. A significant reduction in ED use because of receiving home palliative care was found only in Brumley 2007, where 20% of intervention patients had ED visits during the study period as opposed to 33% of those in usual care. • Both RCTs examining the effect on intensive care use found no significant differences between intervention and control groups **Admission to other care service** • fewer home palliative care patients were admitted to a nursing home in the month before death as compared to those receiving usual care (n= 1 study). However, the difference lost statistical significance when adjusted for other predictive factors (age, having home care at trial entry, living with a spouse, and having a gastrointestinal or lung cancer diagnosis). • The evidence was inconclusive on the effect of home palliative care compared to usual care on the number of days spent in nursing homes (two RCTs), hospital admission (10 studies), length of hospital admissions (two RCTs), length of last hospital admission before death (two trials), hospital inpatient days (nine RCTs), proportion of time the patient spent in hospital (two trials) and overall institutional days (three trials and one CBA) • Five RCTs and one CBA provided inconclusive evidence on the effect of home palliative care compared to usual care on outpatient clinic visits. • There was moderate evidence from the US showing no statistically significant differences in referrals to hospice care (2 studies) and limited evidence of no statistically significant differences in the use of private home care (1 study) and night sitting (1 study). The evidence was inconclusive for all other community services measured including physician visits (five trials), nursing care (five trials and one CBA), social services and home workers.
Secondary outcomes	A team delivering home palliative care with the presence of the following four elements: • Primarily for patients with a severe or advanced disease (malignant or non-malignant), no longer responding to curative/maintenance treatment or symptomatic (or both), or their family caregivers, or both. • Aiming to support patients or family caregivers, or both, outside hospital, and other institutional settings as far as possible and to enable patients to stay at home. • Providing either specialist or intermediate palliative/hospice care, as defined in a previous systematic review: ○ specialist palliative/hospice care was defined as health and social care provided by one or more doctors who have undergone higher specialist training in palliative medicine, and one or more nurses who have undergone higher specialist training, and one or more professionals attached to the team from a profession allied to medicine who have had further training in palliative care. ○ intermediate palliative/hospice care was defined as health and social care provided by: professionals from differing clinical disciplines working full-time or most of the time in palliative/hospice care, who have not undergone any higher specialist training but developed much clinical experience over the years and had in-service training for their job, or a monodisciplinary team of professionals (e.g. nurses) working full-time or most of the time in palliative care, in which one or more members may have had some further training.

	• Providing comprehensive care and aiming at different physical and psychosocial components of palliative care
Authors' conclusion (+ discussion)	The results provide clear and reliable evidence that home palliative care increases the chance of dying at home and reduces symptom burden for patients with cancer, without impacting on caregiver grief. This justifies providing home palliative care for patients who wish to die at home. More work is needed to study cost-effectiveness especially for people with non-malignant conditions, assessing place of death and appropriate outcomes that are sensitive to change and valid in these populations, and to compare different models of home palliative care, in powered studies.
Comments	Other outcomes, such as symptom burden, caregiver grief are not reported in this evidence table.

Grant et al., Public perceptions of advance care planning, palliative care, and hospice: a scoping review, 2021[61]	
Type + number of included studies	Systematic review (n=1), quantitative studies (n=?), qualitative studies (n=?), total number of studies (n=12), search 2011-2020
Type of participants (+ setting)	Lay public (adults) from US
Intervention v (s comparator)	Public perceptions of ACP, palliative care, and hospice
Primary outcomes	**Perceptions of palliative care** • Public is unfamiliar with PC. **Perceptions of hospice care** • High public awareness and public favourability of HC • Higher among participants with more education or personal experience • Minority with misconceptions: beliefs that choosing hospice was tantamount to "giving up". **Factors influencing public perceptions** • Facilitators: older, white females with higher education and socioeconomic status; personal experience with a family member that was positive; trust in the health system; presence of a strong relationship with a primary care or other clinician • Barriers: barrier to discuss serious illness; distrust of documents; mistrust in the health care system
Secondary outcomes	**Perceptions of ACP** • Gap between high awareness (80-90% aware of ACP and think it is important) versus low action (minority having named a health care proxy decision maker or completing a written directive) • Reasons for taken action: past experiences (being asked to make decisions for family member who had not left any indication of their wishes for EOL care) • Reasons for not taken action: mistrust of the health system that their wishes would be followed, confidence that those who mattered to them already knew what they wanted, and inability to at because of other life stresses
Authors' conclusion (+ in discussion)	The challenge facing messaging for PC is "low awareness/common misconceptions": few among the public are aware of PC and of those who are aware, most hold an incorrect view that PC is about dying.

	The challenge facing messaging about HC is “high awareness/significant reservations”: most of the public are aware of hospice but a significant minority have had negative personal experiences with hospice or hold incorrect views about what hospice provides.
Comments	/

Hanan et al., Hospice use among individuals with severe persistent mental illness, 2021[49]	
Type + number of included studies	Quantitative studies (n=7), mixed methods (n=1), total studies n= 8, no search date specified, thematic analysis
Type of participants (+ setting)	Individuals with severe persistent mental illness (SPMI), including schizophrenia, schizoaffective disorder, bipolar disorder, major depression and obsessive-compulsive disorder, US, Canada, Taiwan, New Zealand
Intervention (vs comparator)	Use of hospice services or palliative care services* at end of life in people with SPMI vs general population
Primary outcomes	**Discrepancies in hospice use (by people with SPMI)** • Use of services: less likely to receive (specialist) palliative care services + less likely to see specialist health care professionals + lower rates of referrals to palliative care (may be associated with lack of family support) • Place of death: more likely to die in nursing homes, lower rate of in-hospital death in cancer patients with SPMI vs cancer patients. • One study (in Taiwan) found no significant differences in overall use of palliative care or hospice between individuals with and without schizophrenia in the last month of life, however fewer consultations with palliative care professionals and higher rate of ICU utilization and more likely to receive interventions, such as cardiopulmonary resuscitation, intubation, mechanical ventilation and feeding tubes, were reported
Secondary outcomes	**Inadequate communication about end-of-life care** • Related to psychiatric symptoms: disorganised thought patterns, behaviours and symptoms associated with SPMI may complicate assessment and interpretation of physical symptoms→ less trust and therapeutic alliance with healthcare professionals, absence of a feeling of safety for both patient and provider, discussions about symptom management and ACP may not occur. • Related to healthcare provider factors: concerns about competency and emotional vulnerability of patients→ exclusion from EOL care decisions. **Need for advance care planning** • family communication problems and estrangement, guardianship status, assumptions regarding capacity to participate in EOL care decision-making→ underlying question of competency. • absence of representative to facilitate communication about care preferences: conversation may not take place or only late in the course of illness. • factors related to a decreased frequency of having completed advance directives: difficulty of establishing rapport between individuals with SPMI and their healthcare professionals, individuals’ potential inability to refuse invasive procedures, lack of caregivers or advocates due to frequently being single and being estranged from family.

	• very few individuals with SPMI had discussed their preferences for EOL care and only 5% reported having had a conversation with their physicians about this. **Fragmentation of care** • inadequate coordination of care, lack of clarity about patients' preferences and plans for care, discontinuity in service delivery (due to inconsistencies in how and what type of care is delivered) → may hinder referrals to hospice and palliative care services. • one Canadian study: individuals with SMPI more visits to general practitioners and psychiatrists, but lower rates of seeing other specialists, receiving opioids for pain relief, and receiving palliative care. • reluctancy of professionals outside psychiatry or hospice to care for individuals with SPMI due to inexperience and discomfort
Authors' conclusion (+ in discussion)	Inadequate communication, the need for advance care planning, and fragmentation of care appear to affect the ways in which hospice care is accessed, utilized, and missed.
Comments	*Data on the use of palliative care analyses when utilized for symptom management and comfort at the end of life No data on homeless patients with SPMI

Hughes et al., What do patients and family-caregivers value from hospice care? A systematic mixed studies review, 2019[8, 57]	
Type + number of included studies	Qualitative studies (n=17), quantitative studies (n= 10), mixed methods (n=7), total studies (n=34), search up to 2017, mixed-method synthesis
Type of participants (+ setting)	Adult patients residing in hospice services, UK, Ireland
Intervention vs comparator	Patients 'and their family carer views and experiences about hospice services in the UK
Primary outcomes	**The importance of staff in the provision of high standard quality care** • Personal and professional traits of hospice personnel: personal qualities of staff, their experiences and specialised knowledge and skills, development of a close rapport amongst staff-patients-their families ('turned out to be friends') • Specialised knowledge and expertise: enhanced ability of staff to empathise, use their initiative, anticipate the changing needs of the patient and their families, and provide proactive responses. • Regular contact with designated key personnel: to learn the nuances of individual patients and to provide the necessary support tailored specifically to them. **The importance of the role of social engagement and participation in social activities in the maintenance of relationships and their sense of normality** • Sense of community in day units: to sit together + frequent use of collective terms ('we, us') • Peer support: to hold open discussions with each other, enabled patients to share their stories and reduces social isolation. **The importance of the comfort gained from the availability and accessibility of the hospice** • Sense of security: 24h support by staff, open visiting hours, access to wide range of staff and services

	• Help for families in continuing their caregiving role: provision of phone support, addressment of worries, general support, reassurance, validation and help with practical tasks, provision of hospice night aides. • After death support: support following home death (arranging funerals, returning medical equipment, difficulties seeking bereavement support) **The importance of the role of the hospice in helping promote patient and carer autonomy through the provision of various support mechanisms.** • Support for the informal caregivers' ability to cope physical, psychological, social, and financial help, domestic-related support (also often done by night aides) • Respite care
Secondary outcomes	**The quality of care provided.** • High standard of care: highest when care provided by hospice setting. • High levels of satisfaction • Knowledgeable, courteous, and approachable staff: patients and caregivers with high levels of confidence in their capabilities • Minimal discrepancies found between hospice and hospital staff in relation to friendliness, approachability, and helpfulness (spouses' perspectives) **Availability of the hospice and its staff** • Emphasis placed by patients on availability of staff: adequate number of staff, could reach hospice medical team, when necessary, the hospice team provided the help requested. • Discrepancies between hospice and hospital: staff availability is greater in hospice and spouses reported more likely to talk to wider range of staff whilst at hospice. **Provision of information** High levels of satisfaction regarding receipt of adequate information: suitable updates, explanations about patient's condition, treatment, and tests in a clear and comprehensible way • Caregivers twice as likely to be kept informed within hospice vs hospital. **Patient and informal caregivers views on their involvement in the care** • Both in hospice day care setting and in inpatient setting: high percentage of those 'very satisfied' with their involvement in the planning of their care • Involvement in shared decision-making process higher in hospice compared to hospital. **Bereavement support** • In older studies: no systematic attempt or only informal asked to remain in contact, to support bereaved spouses. • In more recent studies: majority of respondents received follow-up call as minimum level of support. Other services were monthly memorial ceremonies (with high attendance rate), a volunteer bereavement support service, a bereavement information evening (with relatively low attendance rate), due to lack of awareness of support networks available. **The accessibility and quality of food** • Within day care setting: being welcomed on arrival with tea and scones and lunch most valued.

	• Within inpatient setting: similar rates of respondents who considered the quality as 'excellent' between inpatient and day care settings + large proportion of patients happy with their access to food outside of set mealtimes. • Majority of informal caregivers reported that their loved one had received the necessary support needed to alleviate hunger and thirst. Only small proportion felt strongly that the patient had not received adequate support to address these needs. **Respect and dignity** • Most informal caregivers believed hospice patients were 'always' treated with dignity (similar rates in day care and inpatient settings) vs only half of the respondents in hospital setting. **Symptom relief** • No significant difference in pain control measures between hospice and hospital (from perspective of bereaved relatives) • Differences in effectiveness of pain relief: informal caregivers were more than twice as likely to report pain had been relieved 'completely all the time/completely some of the time' within hospice vs in hospital. • Spouses were less likely than those elsewhere to worry about a patient's pain or its relief. **The provision of hospice transport** • More than half of the respondents rated punctuality, comfort, and safety of hospice transport as excellent. • About 40% of the patients most valued their journey to the hospice and to home as most valued activities **Visiting hours** • Open visiting arrangements were appreciated by both informal caregivers and patients. • More time (hours a day visiting) was spent by informal caregivers in hospice compared to hospital. **Respite** • Respite care for informal caregivers: one of the reasons for referral to day care. • Conflicting evidence found on benefits: large proportion of informal caregivers found it beneficial vs similar rate of respondents showing improvement or even negative change in stress score. **Social opportunities** • Provision of social opportunities: considerable value to both patients and informal caregivers • Patients valued "quiet time to chat" and the opportunity to meet people
Authors' conclusion (+ in discussion)	Overarching findings: **Equity in the provision of support is an essential value to ensure patients and their family caregivers are receiving timely interventions day or night.** • Hospice at home service: ensured their loved one to remain at home + prevents unwanted hospital admissions. • Conflicting evidence on satisfaction: positive vs reports of abandonment in times of need, could be due to inequities of the available services (such as access to out-of-hours support due to geographic variations) and lack of awareness of services provided by hospice. **Informal caregivers appeared to place high value on bereavement support, but the reactive nature of the service resulted in informal caregivers foregoing support.**

	• Informal caregivers placed high value on bereavement support but did not always receive it, mainly due to lack of contact from the hospice following the death of a family member. • Evidence shows different forms of post-bereavement support (see above), but emphasis on proactive nature (highly valued by informal caregivers and high attendance rates) • Gradual readjustments to life without hospice involvement: starting with minimal level of support and facilitated through the provision of pre-bereavement support prior to death, which can help enhance the caregivers' preparedness and acceptance. **Informal caregivers appeared to place high value on proactive support, but they did not always consistently receive it.** • High value on staff acknowledgement of carer needs and on respite care. • However: provision of some support mechanisms was likely to be reactive as opposed to proactive **Choice was a consistent value to patients thus creating a need for a wide range of activities.** • Significant value on having access to a wide range of activities but low level of satisfaction on available activities. • Emotional and social needs are met, but in a lesser amount the physical needs: some respondents indicated that they would like access to activities to help keep fit. **Informal caregivers valued the provision of social opportunities and could therefore benefit from access to official social support networks.** • Help received had positive influence on informal caregivers' ability to cope. • Improvements needed in availability of social support: caregivers were not accessing official social support networks prior to death of loved ones + psychosocial pressures + feelings of social isolation + challenging to converse with family members→ provision of a support network which extends beyond the family has increased benefits (e.g., shared rooms)
Comments	Findings show pivotal attributes associated with a 'good death' irrespective of the setting. The concept of a good death can be complex and highly individual, therefore the importance of neglecting a 'one size fits all' approach to care in favour of a system which offers continuous holistic assessments in response to the changing needs of both the patient and their family. Lack of evidence to demonstrate the importance of hospice volunteers in helping to deliver support, however, could be due to patients and family caregivers having difficulty distinguishing between those who are staff and those who are volunteers.

Hughes et al., The effectiveness of community-based palliative care programme components: a systematic review, 2023[8]	
Type + number of included studies	N= 57 studies (n= 25 quantitative studies, n= 21 qualitative studies, n= 11mixed methods), search up to 2021
Type of participants (+ setting)	?
Intervention vs comparator	A single, specific component of a community-based palliative care program (e.g. music program) vs? Comprehensive community-based pc programs with multiple components were excluded→ see Vernon, 2022[8]
Primary outcomes	**Healthcare utilisation and patient outcomes** • **Early community-based PC intervention*: all 5 studies showed positive effects** ○ Lower ER use ○ Lower acute care stays in last 2 weeks of death ○ Improved symptom distress/HIV self-management understanding at 9 months into the program compared to beginning of program. • **Education (n=11 studies)** ○ Quantitative studies (n=6): increased knowledge for the learners (n=6 studies) + increased competence or skill (n=2 studies) ○ Result from qualitative studies not mentioned. • **Telehealth (n=7 studies)** ○ Positive acceptability and feasibility findings, no studies yet on efficacy • **Standardised communication sessions among community-based pc team participants (n=6 studies) (e.g. interdisciplinary team meetings discussing patients): most reported positive results** ○ Increase in respecting a patient's life will, home deaths and hospital utilisation rates. ○ No positive impact on quality of life (n=1 study) • **Volunteers (n= 9 studies): almost all studies positive effects** ○ Positive experience from perspective of volunteers, patient/caregivers and involved medical professionals. • **Innovative approaches: service provision** (n=12 studies)** ○ Positive outcomes on cost-effectiveness, patient/caregiver satisfaction and hospitalisation rates • **Innovative approaches: personnel roles (n=8 studies)** ○ Nurse-led program roles: no improvements in QoL, conflicting results for home deaths and hospital utilisations rates, high satisfaction rates in patients and staff
Secondary outcomes	/

Authors' conclusion (+ discussion)

Programme component	Results	Relevance to practise
Early intervention	—Lower emergency department use —Fewer acute care stays —Symptom distress/disease understanding improved	Start palliative care as soon as it is apparent the patient needs such services
Education	—Increased learner knowledge —Increased learner competence or skill	Train palliative care team members, volunteers and students in palliative care topics; it may improve their knowledge, confidence and skills
Telehealth	—Using telehealth is feasible and acceptable —Increased patient access to services —Improved patient satisfaction	Use telehealth to potentially augment palliative care services, being mindful of facilitating access to such services by making technology training and electronic devices available
Standardised sessions	—Increased respecting patient's life will —Increased home deaths —Lower hospital utilisation rates	Conduct interdisciplinary team meetings that are planned in advance and focus on patient-related concerns
Volunteers	—Positive experiences reported by volunteers, patient/caregivers and medical professionals	Engage and train volunteers to assist with palliative care to increase and enhance the provision of services
Innovative approaches (service provision)	—Overall, positive experiences were reported by patients/caregivers	Testing innovative approaches (e.g. music therapy) in community-based palliative care may lead to improvements in outcomes and patient and caregiver experiences
Innovative approaches (personnel roles)	—Overall, a lack of improvements	Establishing new types of personnel roles within community-based palliative care may not be the best use of resources until further research can determine the value of specific roles

Source: retrieved from Hughes et al., 2013

This systematic review reveals that certain components (standardised sessions, volunteer involvement and early intervention) of community-based PC programs improve health outcomes, such as home deaths, hospitalisations, and patient/caregiver satisfaction. Quality of life-related outcomes proved more difficult to improve wit community-based PC components.

Standardised sessions stood out among the categories of program component types: quantitative outcome measures (home deaths, hospitalisations, performance of activities of daily living scores) improved + qualitative studies showed appreciation among workers for support and knowledge transfer + studies showed that sessions are relatively cost-effective. Only patient quality of life was not statistically different across multiple studies.

Comments

*'early' defined as in advance of a patient needing to make final decisions regarding PC: in 3 studies 2-3 months before death, in 2 studies early intervention happened before the individual's disease continued to progress

** not clearly defined or described in review

Poorly reporting of results, which hampered analysis per community-based pc component or per outcome

Husebo et al., The Liverpool Care pathway: discarded in cancer patients but good enough for dying nursing home patients? A systematic review, 2017[29]	
Type + number of included studies	N= 12 studies, no search date reported
Type of participants (+ setting)	Nursing home patients and people with dementia
Intervention vs comparator	Liverpool Care Pathway vs usual care
Primary outcomes	Some organisational outcomes reported across the included studies, no meta-analysis performed: - Scotland: a general increase in do not attempt resuscitation orders and ACP, reduction in hospital admission or hospital deaths
Secondary outcomes	**Barriers of implementation described in included studies** - (Scotland): lack of knowledge regarding palliative care, drug use and symptom control in the NH, staff may not be able to recognize when dying is imminent and thus the necessary preparation would not be possible, lack of understanding the dying process, possibly because NHs has been under-resourced for a long time; lack of a multidisciplinary team with shared decision making, training in communication, and readiness and ability to change. - The Netherlands: no differences found in communication and EOL care in NHs, compared to baseline
Authors' conclusion (+ discussion)	LCP has not been adapted to nursing home patients and people with dementia. Current evidence, i.e. studies investigating the validity and reliability in clinically relevant settings, is too limited for the LCP procedure to be recommended for the population at hand. There is a need to develop good practice in palliative medicine, Advance Care Planning, and disease-specific recommendations for people with dementia
Comments	Organisational outcomes not clearly reported, making conclusions difficult

Iupati et al., Systematic review of models of effective community specialist palliative care services for evidence of improved patient-remated outcomes, equity, integration, and health service utilization, 2023[10]	
Type + number of included studies	N= 42 studies (n=8 SRs, n=34 primary studies of which n=24 observational studies, n=5 RCTs, n=5 qualitative studies, n= 3 paediatric studies), search 2012-2019
Type of participants (+ setting)	(adults and paediatric) Patients who receive specialist palliative care services in the community, informal caregivers receiving care or nonspecialist palliative care professionals (e.g. primary care) accessing support services from community-based specialist palliative care professionals, studies performed across 14 countries, with majority in the United States.
Intervention vs comparator	Effective models of community specialist palliative care services vs usual care, historical comparison
Primary outcomes	**Utilization of hospital services** • N=4 RCTs: 3 studies reported statistically significant positive effect of SPC (reduced hospitalizations), 1 trial nonsignificant negative effect • N=8 observational studies: all 8 studies showed statistically significant reduction in hospitalization with SPC, 3 studies showed significantly reduced ED visits

	• N=8 reviews: 3 reviews reported a reduction in hospital length of stay with specialist palliative care but conflicting evidence regarding hospital admissions **Integration of specialist with nonspecialist palliative care services:** not reported in the studies
Secondary outcomes	**Patient-related outcomes** • QoL ○ N=5 RCTs: 4 studies reported beneficial effects of SPC, 1 significant negative effect ○ N:3 observational studies: 1 study showed a trend favouring intervention, 2 studies no difference ○ Patient/caregiver education significantly improved average daily symptom burden ○ In most trials face-to-face care, in 1 trial telehealth intervention with significantly worse symptom scores • Qualitative studies: ○ Patients generally found benefits of care coordination enabled patients to stay at home by providing adequate resources while creating partnership. ○ Family and caregivers experienced enhanced emotional well-being or sense of relief. These were achieved by witnessing patients' enhanced well-being, shared responsibility, ability, and flexibility to stay at home, provided time and space to live through last stages of their relative's life in their own home, offered a sense of control, tailored to specific needs, and improved communication with other health service professionals e.g., primary health care professionals. ○ Patients and families attribute positive experience to various practical help they get from specialist palliative care services e.g., providing resources such as equipment, hands-on care by formal caregivers relieving care burden, continuity of care by the same individuals providing care, social services relieving financial burden, after-hours support, staff identifying and treating depression, assisting with medical tasks such as medications and access to medical services, medical crisis management ○ Barriers to positive experience include unmet need, failure of health care professionals to meet expectation or not listened to, assumption of palliative care only providing end-of-life care resulting in late engagement. Services can be improved by more information about prognosis, fewer health care professionals coming to patients' home, for family to receive emotional support too during health professional's visits. • N=8 reviews: 7 reviews showed positive effect of palliative care program on home deaths and symptom burden **Caregiver-related outcomes** • N=1 RCT on teleconsultation: trend toward a clinically meaningful reduction in caregiver burden in the intervention group **Equity measures** • N=2 RCTs showed non-statistically significant trends favouring intervention
Authors' conclusion (+ discussion)	This review finds a high level of evidence from RCTs that community specialist palliative care improves patients' symptom score/quality of life and reduces secondary service utilization when compared with usual care. This is also supported by positive trends found in observational studies and systematic reviews included in this study. There is strong evidence of benefit for face-to-face patient care, while the evidence base for consult/advice to other health professionals and telehealth is small.
Comments	Definitions:

	• Community: outside of hospital settings • Specialist palliative care: those with specialist staff in the multidisciplinary team, for example palliative care nurses or physicians. Also including presence of higher specialist training in palliative/hospice care or training in "care of the dying" • Models of care: providing a framework of a system for the organisation of care for people with progressive life-limiting illness and/or support for family, informal caregivers, or close friends, moreover the model needed to be multifaceted and multidisciplinary, and should involve multiple components, including who delivers, the intervention, setting, care recipients, when, how, and for what purpose.

Johansson et al., A rapid systematic review of the effectiveness of out-of-hours palliative care telephone advice lines for people living at home and their informal caregivers, 2023[16]	
Type + number of included studies	N= 21 studies (n= 8 quantitative studies, n=5 mixed methods, n=1 qualitative study), search up to 2023
Type of participants (+ setting)	People with palliative and end-of-life care needs in the community and their informal caregivers, UK, Australia, USA, Canada, The Netherlands, Singapore, Taiwan
Intervention vs comparator	Any telephone advice line that is: available through telephone calls, designated for providing palliative care support, help, and information, reactive, i.e., contact is patient/carer initiated, accessible during at least parts of the out-of-hours periods (weekdays between 18.30-08.00, weekends, and public holidays)
Primary outcomes	**Service use** • 19-69% of calls were received during out-of-hours periods, most out-of-hours calls (35-78%) were received on weeknights before midnight • callers were primarily identified as family members or informal caregivers (ranging 45-88% of calls) • The most reported call reason was managing symptoms and/or medication (n=10), with other reasons involving health deterioration, nursing advice, requests for new or additional medication or equipment, or reporting that the patient had died • Data about when in the care trajectory calls were made were scarce: one study found that median time for accessing the telephone advice line was 10 days before death and another study reported that most calls occurred between the first days of home hospice admission and the last three days of life. • the most reported actions taken by responders involved providing support and nursing advice appropriate to their level of clinical training and transferring or signposting callers to other services. Responders in some telephone advice lines also contacted on-call teams for urgent home visits (n=5), arranged next working-day follow-up at home or over the telephone (n=9), and, less commonly, helped with prescribing or collecting medication (n=4). Ten studies reported that responders successfully handled many calls directly through over-the-phone support. In cases when a responder could not adequately help a caller, calls were usually passed on to more senior healthcare professionals, commonly senior palliative care nurses, clinical nurse specialists, or GPs, who were either available on-call or in-house (n=11). These professionals could generally provide more advanced medical advice, arrange home-visits, make referrals, and occasionally, prescribe or dispatch medicines. However, the proportion of calls passed on was rarely reported. **HC utilization:** patients who accessed telephone advice lines were:

	• less likely to use emergency care services (n=2 studies) • less likely to call for an ambulance or visit an emergency department (n=1 study) • less likely to be admitted to hospital in the last week of life and to die in hospital (n=1 study) • overall, only between 1.5-9.0% calls led to hospitalization or admission of patients. This suggests that hospitalisation is infrequent following out-of-hours calls, although the lack of data makes it hard to determine the effect of telephone advice lines on subsequent admission. 73-95% of patients who contacted the telephone advice line remained at home 24 hours after the call (n=3 studies). **Cost effectiveness** • very scant evidence regarding costs or cost effectiveness of telephone advice lines: three studies presented rough estimations of costs associated with implementing telephone advice lines within a specific service, suggesting they were generally 'resource-effective' for providing palliative care during out-of-hours periods. • conflicting evidence found on potential cost-savings by less use of avoidable emergency care however also slightly higher costs found regarding out-of-hours access to medicines for patients at home
Secondary outcomes	**Main characteristics of the telephone advice lines:** • 13 of the telephone advice lines were available for calls 24/7 and six were available during parts of the out-of-hours periods. One study did not state availability. • Fifteen of the telephone advice lines were accessible only for patients known to palliative care services (and their informal caregivers) or listed on palliative care registers, but information on how they were promoted or explained to patients and informal caregivers was uncommon. • Information about the structure of the telephone advice lines was scant. Less than half of the studies described the location and coverage of the telephone advice line. • Most services were not diagnosis-specific, with just one being restricted to cancer patients. When reported, telephone advice lines were either financed by time-specific grants or funded internally by the service. **Patient-related outcomes:** • A recurring finding was that the telephone advice lines provided valuable opportunity for patients and informal caregivers to ask about signs and symptoms and be informed about the disease trajectory or the dying process, so that callers can better understand whether these are 'normal' or expected. • Receiving appropriate information was also reported to aid decision-making and help prevent unnecessary hospital admission and promote appropriate use of care services, as patients and informal caregivers noted that they might otherwise have contacted emergency care services. • callers' sense of comfort when responders were familiar to the patient's case. Similarly, access to patient records was described as valued by callers who did not have to re-explain the situation. • User experiences were overwhelmingly positive. Calls were generally triggered by a patient crisis or carer uncertainty. Both patients and informal caregivers emphasised feeling reassured by the knowledge that the service was available for them whenever they might need it, both in medical crises and when the caller was feeling uncertain or worried
Authors' conclusion (+ discussion)	Existing evidence for the effectiveness of telephone advice lines is limited. The lack of experimental studies evaluating individual, or system-level outcomes prevents assessment of the effectiveness/cost-effectiveness of service models.

	As reported in existing literature: integration with other services, e.g., the extent to which patient records were accessible to staff responding to calls and shared with other health care professionals. Inadequate integration with the wider health care system has previously been identified as contributing to inequity in access to community-based palliative care and may limit benefits for patients and informal caregivers.
Comments	A broad definition was used to allow assessment of various types of telephone advice lines, provided there was a 'reactive' component (i.e., contact is patient/carer-initiated, as opposed to pre-booked appointments).

Johnston et al., Effectiveness and cost-effectiveness of out-of-hours palliative care: a systematic review, 2020[14]	
Type + number of included studies	N= 1, search 2000-2019
Type of participants (+ setting)	Adults in their last year of life and/or had a terminal illness and/or had other serious/complex medical needs, and/or were a carer for someone who met these criteria
Intervention vs comparator	Out-of-hours specialist or generalist palliative care vs usual care or alternative models of out-of-hours palliative care
Primary outcomes	/
Secondary outcomes	/
Authors' conclusion (+ discussion)	We identified no study of sufficient quality that evaluated the effectiveness or cost-effectiveness of out-of-hours specialist or generalist palliative care for adults. This study illustrates that while out-of-hours palliative care is a recognised priority for patients and policymakers, no evidence base exists on which services are beneficial for patients and worthy of health care funding.
Comments	Definition of out-of-hours: outside of typical working hours (i.e. 9.00am–5.00pm, Monday to Friday) and therefore including overnight, weekends, and public holidays

Joseph et al., The effectiveness of structured interdisciplinary collaboration for adult home hospice patients on patient satisfaction and hospital admissions and re-admissions: a systematic review, 2016[32]	
Type + number of included studies	N= 0 studies, search up to 2014
Type of participants (+ setting)	Adults, male and female (18 years old or older), receiving home hospice services or transitioning from hospital to home hospice services
Intervention vs comparator	interdisciplinary collaboration among the hospice team providing home hospice services in the home care settings
Primary outcomes	No studies met the inclusion requirements. There were no text or opinion pieces that were specific to structured interdisciplinary collaboration among the hospice team in home care settings on patient satisfaction and hospital readmission.
Secondary outcomes	/
Authors' conclusion (+ discussion)	There is currently no evidence available to determine the effectiveness of structured interdisciplinary collaboration among hospice teams in home care settings regarding patient satisfaction and hospital readmission.
Comments	/

Khandelwal, Estimating the effect of palliative care interventions and advance care planning on ICU utilization: a systematic review, 2015[20]	
Type + number of included studies	N=22 (n=9 RCTs, n=13 nonrandomized controlled trials), search 1995-2014
Type of participants (+ setting)	Critically ill adult patients
Intervention vs comparator	Advance care planning, primary and specialty PC interventions, ethics consultation about goals of care in outpatient, acute care, and ICU settings *Primary PC defined as PC or communication interventions provided by nonpalliative care specialists such as family meetings *Specialty PC defined as PC provided by PC specialists
Primary outcomes	**Reduction in ICU admissions** • RCTs: (n=1) routine PC consultation in hospitalized patients vs usual care: fewer ICU admissions (5% vs 10% in usual care) • Non-RCTs (n= 3) ○ PC consultation in hospitalized veterans vs usual care: 33% ICU admission vs 68% of patients receiving usual care (adjusted risk reduction of 42% (95% CI, −56%, −31%) in ICU admissions for patients who received a PC consultation) ○ Larger observational study in hospitalized veterans: ICU admission in 33% vs 37% receiving usual care (adjusted risk reduction of 44% (95% CI, 49%, 39%; p < 0.001) of being admitted to ICU during same hospitalization) ○ Mean relative risk reduction for all 3 studies 37% **ICU length of stay**

	• Interventions in acute care and outpatient settings (only 2 RCTs found) ○ Inpatients >80y with ACP intervention vs usual care: mean ICU LOS 5.3 days vs 10.9 days in usual care (relative risk reduction for all patients 52%; no p-value reported) ○ Outpatients with new diagnosis of life-limiting cancer with routine multicomponent PC consultation (4 weekly educational sessions) vs usual care: no difference in ICU LoS (0.06 d for both groups; p = 1) • Interventions in the ICU setting ○ RCTs (n=4) ethics consultation vs usual care: inconclusive results (2 studies reported significant reduction in ICU LoS (4.2 days vs 13.2 days) vs no difference between intervention and control group). One study with multifaceted quality improvement intervention to improve PC skills of ICU clinicians: no difference in LoS ○ Non-RCTs (n=10): 8/10 reported decrease in LoS in PC intervention (communication intervention; PC consult; family meeting). In the 2 studies with no difference: full-time family support coordinator in ICU team vs UC and intensive communication strategy in ICU vs UC ○ Mean relative risk reduction for ICU LoS for all interventions was 26%
Secondary outcomes	/
Authors' conclusion (+ discussion)	Two important trends emerged from results (although significant variability was present): - ACP and PC interventions reduce the number of ICU admissions for patients at high risk of death - Majority of the studies demonstrated a reduced ICU LoS with ACP or PC interventions
Comments	No meta-analysis due to heterogeneity in study interventions, study design, and study populations

Kim et al., Effect of primary care involvement on end-of-life care outcomes: a systematic review, 2016[19]	
Type + number of included studies	N= 13 studies (n=2 prospective studies), search 1994-2014
Type of participants (+ setting)	Individuals receiving care from a PCP at the end of life, in USA, Canada
Intervention vs comparator	Involvement of primary care professionals
Primary outcomes	**Discharge or death with supportive care** • when PCPs were involved with EOL care, participants were more likely to be discharged from or die out of the hospital (in 8 of 9 studies) • participants with PCPs who made home visits were more likely to die at home than those with PCPs who did not make home visits (in 3 studies) • individuals with more GP visits in the last 3 months of their life were more likely to die at home than those with fewer or no GP visits (in 2 studies) • those with greater PCP continuity in the last 6 months of life were more likely to die out of the hospital than those with moderate or low continuity (in 1 study)

	• those with breast cancer who saw a PCP and an oncologist used hospice more frequently (41%) than those who saw an oncologist and no PCP (38%), although those who saw a PCP and no oncologist had the lowest rates of hospice use (30%) (in 1 study) • people with cancer who were supported by a family physician were more likely to die at home with hospice care (in 1 study) **Admission: ED or hospital** • conflicting evidence reported: 2 studies lower odds of ED or hospital admission, but 2 studies higher odds and one study no association. **Resource use:** • conflicting evidence reported: 1 study reported similar total hospital costs and LoS (GP vs oncologist), other study patients who saw PCP in year before cancer diagnosis more likely to have ICU stays during last month of life and more likely to receive chemotherapy in last month of life
Secondary outcomes	**PCP involvement** • Not uniformly measured across all studies: number of PCP outpatient, home or telephone contacts during specific time frame, involvement of PCP in different care settings, number of family physician professionals involved, number of outpatient visits made. **Symptom management** • Conflicting evidence reported: patients with more than 12 GP home visits more likely to receive opioid treatment (in 1 study), no significant difference in pain ratings between participants seeing PCPs or oncologists (1 study) **Survival rate** • No difference in terms of 30-day, 2-month or 6-month survival rates between PCPs and oncologists
Authors' conclusion (+ discussion)	When PCPs are involved in EOL care, people are more likely to die out of the hospital, with home care, hospice care, or both. Thus, the relationship with the PCP may be particularly important in EOL care because PCPs may help individual establish goals of care and determine treatment preferences.
Comments	/

Leclerc et al., The effectiveness of interdisciplinary teams in end-of-life palliative care: a systematic review of comparative studies, 2014[31]	
Type + number of included studies	N=4 studies, search up to 2013
Type of participants (+ setting)	community-dwelling or inpatients aged 18 and over who had a prognosis of one year or less, had stage iii or iv cancer or a terminal condition, and received care in any setting
Intervention vs comparator	Palliative care from a team included members of at least three professions (consultants, associates, extended team members, and volunteers were not considered as team members; physicians, residents, and specialist doctors were all considered to belong to one discipline). The team involved as "interdisciplinary" or indicated that the team fulfilled at least two of these criteria: meets regularly and has a designated leader or coordinator; develops a common interdisciplinary plan for each patient; provides care that considers the patient's physical, psychosocial, and spiritual needs (that is, takes a holistic approach); identifies patients' goals of care; involves patients and their families in decision making and care planning; has team operating rules or policies; and uses common evaluation tools vs care not provided by interdisciplinary team
Primary outcomes	• **Death at home**: in intervention group more death at home (n= 2 studies) • **Access to hospice:** median number of days from study enrolment to hospice admission (non-significant) lower in intervention group (2 vs 3, n=1 study) • **Use of ED:** a smaller number of visits in intervention group (0.9 vs 2.3; n=1 study) and lower number of patients visited ED in intervention group (20% vs 33%; n=1 study) • **Use of hospital:** lower number of hospital visits in intervention group (2.4 vs 9.4; n= 1 study), less patients hospitalized in intervention group (36% vs 59%; n=1 study), no difference in number of days at hospital found (n=1 study) • **Use of hospice:** no significant difference found in number of patients enrolled in hospice between control and intervention group (n= 1 study); no significant difference found in patients admitted to hospice (n= 1 study), greater hospice length of stay in days found in intervention group (24 vs 12, same study) • **Use of other services:** lower median number of physician visits in intervention group (5.3 vs 11.1, n=1 study), lower number of skilled nurse visits in intervention group (0.9 vs 4.6, same study); higher number of total home health visits in intervention group (35.0 vs 13.2, same study) • **Continuity of services:** higher number of advance directives at discharge in intervention group (224 vs 172, n=1 study)
Secondary outcomes	Patient-related outcomes also reported but not presented in this evidence table.
Authors' conclusion (+ discussion)	Overall, our review supports the effectiveness of palliative care teams in different settings. The fact that we found only a limited number of existing high-quality studies in our review precludes definitive conclusions about the effectiveness of interdisciplinary teams in end-of-life palliative care for adult patients. Nevertheless, our systematic review provides preliminary evidence that interdisciplinary palliative care teams can improve patients' satisfaction and a few organisational aspects of care. thus, our analyses lend support to the argument that funding and developing palliative care teams is a way to improve patient care.
Comments	Difference found in results reported in table and in text.

Lewis et al., Models of care for people with dementia approaching end of life: a rapid review, 2023[26]	
Type + number of included studies	N= 19 studies describing 12 dementia-specific models of EOL care, search 2000-2022
Type of participants (+ setting)	People with dementia in the last year of life, or the palliative phase of the disease, i.e. advanced, severe, or end-stage dementia and/or person assessed as meeting level 6/7 of the Global Deterioration Scale, UK, Australia, US, Singapore, Wales
Intervention vs comparator	A care intervention, variously referred to as a model of care, programme, care pathway, care plan or framework, with multiple components demonstrating care coordination
Primary outcomes	**12 models were identified, but only the models with organismal outcomes were retained in this evidence table.** • Alzheimer's Disease and Related Dementias Palliative Care (ADRD-PC) programme, US, including PC consultation, Phone support, Informational booklet for families, Individualised recommendations for PC domains, Assistance with completing a Medical Orders for Scope of Treatment (MOST) order set, the North Carolina version of Physician Orders for Life Sustaining Treatment (POLST), Recommended referrals to post discharge services, Transitional care training session to PC physicians and nurse practitioners **Organisational outcomes:** no difference found in hospital and ED visits (in 60 days after discharge) **Secondary outcomes**: intervention patients more PC domains addressed, receive hospice, discuss prognoses and goals of care, have MOST at 60day follow-up, make decisions to avoid rehospitalisation. • Challenge Pathway, Wales, including Specialist care, Home-based hospice care, social workers, Dementia Day programmes, peer-support groups, Training for health and social care workers, families, and volunteers. **Organisational outcomes:** number of referrals increased; more dementia patient referred for PC than for EOL support. **Secondary outcomes:** more informal caregivers and healthcare professionals rated the service as helpful. • PEACE, US, including Physical and psychological symptom management, Advance care planning, Education on the disease process, Community resources, Coordination of care, Patient and carer-centred care, Hospice services. **Organisational outcomes: patients in hospice more likely to die in their place of choice.** **Secondary outcomes: high satisfaction rates, informal caregivers continued to experience significant stress.** • Programme Dignity, Singapore, including Regular home visits and phone calls from multidisciplinary team, Assessment, and pharmacological interventions to manage pain and behavioural issues, Carer education and support through counselling and referrals to other community services, after hours support, Direct admission to ward or hospice as required. **Organisational outcomes:** less likely to visit ED, be admitted to hospital ad had lower cumulative LoS, fully enrolled patients had lower costs at 1, 3 and 6 months than partially or non-enrolled patients. **Secondary outcomes:** significant improvement in symptom scores and in caregiver burden after 12 months, significant improvement in QoL **Common elements found across the different models:**

- **Referral and admission to care:** admission based on criteria but none of the models reported analysis regarding accuracy of prognostication (if participants were appropriately identified for the intervention and if they were admitted at the appropriate time based on their level of need)
- **Integration of care:** all models had elements of care coordination rule, interdisciplinary collaboration, and person-centred care but level of integration varied considerably.
- **Evaluation of models of care:** few models used large, robust study designs; most were feasibility studies.
- **Sustainability:** some models ceased operation, or it was unclear if they were still operating

Secondary outcomes

Table 2. Dementia-specific end-of-life model of care framework: 9 domains[a].

Domain (ref)	Components and care considerations
Person-centred care (D1)	Person-centred care, communication and shared decision-making regarding care goals and advance care planning
Family care, grief and support (D2)	Family care and support, communication and involvement in care planning; uncertainty, grief and bereavement
Continuity, coordination and integration of care (D3)	Continuity, coordination and integration of care
Interdisciplinary collaboration and communication (D4)	Interdisciplinary communication and collaboration, organisational and workforce issues including education of care professionals, barriers to integrated care delivery
Education (D5)	Education of the patient, family and carers
Symptom and comfort care (D6)	Optimal treatment of symptoms and providing comfort (e.g. pain, challenging behaviour); avoidance of overly aggressive, burdensome or futile treatment (e.g. nutrition/ feeding decisions); quality of life
Prognostication, death and dying (D7)	Prognostication and timely recognition of dying; preferred place of death
Psychosocial and spiritual support (D8)	Psychosocial and spiritual support
Ethical and practical issues (D9)	Social, legal, ethical, financial, practical (e.g. transport, equipment) issues

[a]Adapted with acknowledgment from the European Association for Palliative Care 11-domain framework for optimal palliative care for older people with dementia.[12]

Source: retrieved from Lewis et al. 2023

- Delivery settings for the models of care included residential aged care (n = 5), hospice (including hospice in the home; n = 5), community and home-based care (n = 9), primary care clinics (n = 2), and hospital (acute care; n = 4) settings. Some models were delivered in multiple settings.
- Analysis and mapping of the included models of care against the nine domains of optimal palliative care for people with dementia showed that not all domains were consistently met. The domain for which there was the least demonstrated evidence was ethical and practical issues (D9), followed by psychosocial and spiritual support (D8) and person-centred care (D1).

Authors' conclusion (+ discussion)

Traditional models of palliative care are designed to be delivered in the last 6 months of life. Given the variable disease trajectory of dementia, a longer-term palliative approach to care is needed for people with advanced dementia. A relatively brief, time-

	limited model of care such as the ADRD-PC programme may provide only short-term benefits for people with advanced dementia; this is acknowledged by the authors of the study. Models built around one care delivery location, for example residential aged care, run the risk of fragmenting care when transitions between care locations are required, for example an acute medical episode requiring hospitalisation. Best practice models of palliative care should be built around the person with dementia, regardless of their care setting, and how long they need to receive care. Most importantly, while best practice models of care should incorporate all nine domains of palliative care, they should also be flexible enough to consider the needs of everyone, particularly regarding psychosocial and spiritual support, and needs relating to self-determination, familiarity, and safety.
Comments	/

Luta et al., Evidence on the economic value of end-of-life and palliative care interventions: a narrative review of reviews, 2021[39]	
Type + number of included studies	N=43 reviews, search 2000-2019
Type of participants (+ setting)	terminally ill adults (18 years old and over) and patients with varying illnesses
Intervention vs comparator	Cost-effectiveness, intervention costs and/or healthcare resource use of palliative and end-of-life care interventions across various settings vs usual care Palliative and end-of-life care models/interventions were defined as "any structured care model involving multiple components, including who delivers (e.g., professionals, caregivers) the intervention (specialist or generalist palliative care), where (e.g., hospital), to whom (care recipients), when (i.e., timing and duration), how (e.g., face to face) and for what purpose (i.e., expected outcomes)."
Primary outcomes	**Home-based services** - Cost-effectiveness: ○ reduction in resource use and costs (n= 1 SR on hospice care delivered at home vs in nursing homes and in dedicated hospice facilities) ○ substantial savings for the health system (n=2 SRs on home-based teams) but in one review conflicting evidence with only 2 of 6 studies providing clear evidence of cost-effectiveness - cost analyses ○ inconsistent evidence found across the SR and across the included primary studies in those SRs: significant improvement in HC use or costs vs no differences. - resource use ○ inconclusive evidence found on HC utilization, LoS and hospitalizations. **Other settings outside the home** - Cost-effectiveness: ○ no significant difference in HC resource use between intervention and control groups (n= 1 SR on psychosocial support for women with breast cancer)

	○ potential cost-effectiveness of short-term PC in MS patients (when caregiver burden was used as main outcome measure) (n=1 SR) ○ inconclusive evidence on cost-effectiveness of clinical nurse specialists (see study of Salamanca et al., 2018[37]) ○ decrease in costs and more effective (incremental QALYs) of pain management strategies (Pain Check and Tackling Cancer Pain Toolkit) vs usual care (n=1 SR) ○ some evidence found on benefits of hospital-based PC consultations on patient outcomes, HC utilization and costs (n=2 SRs) ○ no evidence on cost-effectiveness of ACP (n=1 SR) - cost-analyses ○ hospital-based interventions: reduction of costs (hospital costs, ICU costs) in palliative care consultations ○ inconclusive evidence on cost implications of communication interventions ○ in many studies mix of findings of interventions in multiple settings: lower costs or mixed evidence found. ○ inconclusive evidence regarding cost reduction for specific interventions, including social support, CNSs, case management, communication, specialised palliative care, palliative and hospice care teams, multidisciplinary palliative care interventions and patient and/or caregiver QoL. ○ only limited evidence on ACP: potential cost savings - resource use ○ inconclusive evidence found on HC utilization, LoS and hospitalizations of hospital-based interventions. ○ across multiple settings: inconsistent findings ○ ACP: trend toward decreased ICU admission and ICU and hospital LoS, decreased hospitalization rates.
Secondary outcomes	/
Authors' conclusion (+ discussion)	Overall, most evidence on cost-effectiveness relates to home-based interventions and suggests that they offer substantial savings to the health system, including a decrease in total healthcare costs, resource use and improvement in patient and caregivers' outcomes. The evidence of interventions delivered across other settings was generally inconsistent. Overall, most studies overlooked important costs, including out-of-pocket, hospice and informal care costs. Home-based palliative care may contribute to a dual improvement in quality of care by reducing aggressive medicalization end-of-life and concomitantly reducing costs. Hospital-based palliative care interventions may improve patient outcomes, healthcare utilization and costs. Evidence regarding other approaches is less conclusive.
Comments	Refers to Brereton et al., 2017 (SR on different models of PC)

Masoud et al., Patient awareness of palliative care: systematic review, 2021[60]	
Type + number of included studies	Qualitative studies (n=4), mixed methods (n=1), quantitative studies (n=17), (n=19), search 2000-2021
Type of participants (+ setting)	Type of patients and settings not further explained
Intervention (vs comparator)	Patients' awareness of palliative care
Primary outcomes	Patients' awareness about • the definition and description of PC/hospice care: Some patients defined accurately HC and its components, but in others a lack of awareness about the advantages was mentioned, also misunderstandings about PC and HC (e.g., HC provides services only for patients' relatives and for funeral arrangements, only for elderly, only in nursing homes or as home care for daily living activities and rehabilitation care) • PC/hospice components In some studies: patients had information about several components of PC or HC (treatment management, nursing care, EOL care and pain relief), but limited information about pastoral care, social care, and bereavement care. • Individual or centres providing PC or hospice care. Less than half of the patients knew about healthcare professionals specialising in PC who could provide PC and even less of the patients knew that PC could be received in various settings (special PC services, hospital, or community-based counselling centres or in outpatient units). In another study only 20% knew about PC but had no information about centres providing this type of care. • Interventions implemented to enhance awareness related to PC/hospice. Conflicting evidence found on the effect of video presentation on awareness: improvement vs no improvement. Distribution of information at community level increased the awareness of patients with cancer about PC.
Secondary outcomes	Frequency of patients' awareness about PC or hospice care: • In quantitative studies: more than half of the patients did not have any information about PC or hospice care. • In qualitative studies: patient's lack of awareness or limited awareness about PC
Authors' conclusion (+ in discussion)	In majority of the studies: patients do not have adequate awareness or correct information about PC. Status of awareness depends on previous experience about PC and type of patients (e.g. PC education more integrated in patients with cystic fibrosis). Increasing patients' health literacy requires an identification of patients' misunderstandings.
Comments	Articles in English or Persian languages included. Lack of use of valid tools in many studies

Mathew et al., Economic evaluations of palliative care models: a systematic review, 2020[40]	
Type + number of included studies	N=5 studies, search 2006-2017
Type of participants (+ setting)	Any population group receiving palliative care services
Intervention vs comparator	Palliative care models including home-based, hospital-based, hospice, long-term care (nursing home), outpatient settings (ambulatory care in both hospital and office clinic) vs other palliative care models or usual care or no care
Primary outcomes	**Home-based model** - HC use: o fewer hospital readmissions (n=2 studies, interdisciplinary PC team) o fewer hospital readmissions and ED visits (n=1 modelling study, outpatient PC model vs usual care) - cost-effectiveness o home-based PC cost-effective compared to usual care or absence of care (n=3 studies)
Secondary outcomes	/
Authors' conclusion (+ discussion)	Applicability and generalizability of evidence is uncertain due to small sample sizes, short duration, and limited modelling of costs and effects. Nonetheless, current evidence in this area suggests that palliative care has the potential to be cost-effective and can improve outcomes and quality of life in the last year of life. At the health system level, this information should play an increasing role in informing decisions around palliative service delivery
Comments	/

McCaffrey et al., What aspects of Quality of Life are important from palliative care patients' perspectives? A systematic review of qualitative research, 2016[58]	
Type + number of included studies	Qualitative studies (n=24), search up to 2015, framework synthesis
Type of participants (+ setting)	Adults with a progressive, life-limiting illness, Australia, England, US, Canada, Germany, New Zealand, the Netherlands, South Africa, Sweden, Korea
Intervention (vs comparator)	QOL domains
Primary outcomes	**Cognitive aspects** • Contributions to QoL: 'being mentally alert', having the ability to read and watch television. • Barriers: fear of losing cognitive capacity **Emotional aspects** • Emotions: sadness, anxiety, despair, frustration, fear, guilt, happiness, and uncertainty • Emphasized how essential it is to stay positive. **Aspects of healthcare**

	• Overall aspects: access, coordination, continuity, and quality of care • More specific contributors to QoL: feeling secure due to having ready access to care when needed, fewer visits to healthcare facilities with minimal waiting time, relationship with healthcare staff, consistency (frequent changes in staff members caused participants stress and anxiety), staff members' knowledge, experience, and attitudes towards patients, location of healthcare service provision (hospital, at home) **Aspects of personal autonomy** • Contributors: feeling of control and empowerment (having choice), maintaining independence towards a sense of normalcy and less burden placed on others • Barriers: dependency led to loss of dignity and feelings of frustration **Physical aspects** • Contributors: ability to get around, adequate symptom control • Barriers: uncontrolled symptoms (e.g., breathlessness, fatigue) **Preparatory aspects** • Includes: handing tasks over to other family members, organizing funeral arrangements, saying goodbye to family and friends, resolving outstanding personal issues • Contributors: making arrangements **Social aspects** • Contributors: relationships with others, maintaining intimacy with partners, retaining social networks, staying connected, having a role to play in society→ sense of normalcy • Contributors to a sense of self-worth: being treated with respect, maintaining dignity. • Barriers: concerns becoming a burden to others, wish to avoid creating hardship for their family and friends **Spiritual aspects** • Contributors: hope, comfort, meaning (to life), purpose • Organised religion: providing emotional support and comfort, and a sense of community. • Access to nature: highly appreciated and needed
Secondary outcomes	/
Authors' conclusion (+ in discussion)	The findings from this systematic review suggest physical abilities, personal autonomy, emotional state, socializing, spirituality, cognition, health care provision, and preparation for death are important aspects of quality of life for people with a life-limiting illness receiving palliation from their own perspective.
Comments	/

Nelson et al., Sociodemographic disparities in access to hospice and palliative care: an integrative review, 2021[44]	
Type + number of included studies	Quantitative non-experimental studies (n=16), qualitative studies (n=3), mixed-methods study (n=1), search up to 2020
Type of participants (+ setting)	Majority of participants being white or Caucasian, marginalized populations were most commonly Black and Hispanic. One study targeted a variety of Asian ethnicities, only study focused on Native Americans.
Intervention vs comparator	Disparities in access to hospice and palliative care
Primary outcomes	**Impact of access disparities on patient outcomes (quantitative findings)** • Significant differences in outcomes across racial or ethnic minority groups and/or by socioeconomic status (SES) • Low SES: more likely to have high-intensity interventions, hospital admissions, ICU stays in last 30 days of life + less likely to engage with palliative care or enter hospice. • One study: Blacks are more likely to receive an inpatient palliative care consult and/or be referred to hospice. This could be due to professionals more likely to place a consult for patients with Medicaid insurance (which are primarily Black) given the systematic coverage for hospice services. • Association between sex and service utilization (females tend to use services more than men) more pronounced in older patients. • Geographic availability of hospice and PC programs significantly associated with older aged residents, higher household income, urbanicity and less racial diversity of counties or cities. **Key stakeholder perspectives on access disparities (qualitative and mixed methods)** • Common barrier: lack of knowledge and misconceptions about services and options • Delayed referral to hospice/PC services due to medical hierarchy across specialties, difficulty delineating when to refer patients to hospice versus involving palliative care. • Communication barriers, cultural insensitivity, lack of clarity, poor use of translators, overuse of medical jargon • Suggestion for improvement: ○ Enhanced integration of end-of-life care in medical training ○ Expansion of 'pay-for-performance' programs may incentivize hospitals and professionals to enhance access to HC and PC services for patients
Secondary outcomes	**Disparities in access by demographic group** • Different outcomes based on participants' race or ethnicity, socioeconomic and/or insurance status. • Disparities by either disease type or severity: e.g., patients with gynaecologic, breast and stomach cancer were more likely to have PC access than other types of cancer or other diseases. • Less common differences in access by age, gender, and educational level • Differences in access found due to geographic location and/or proximity to an urban area, heredity, political ideations, marital status, inconsistent messaging, comorbidity burden
Authors' conclusion	Hospice and palliative care access is complex and multifaceted. Variation in messaging, socio-cultural factors, funding models, organisational guidelines and personal preferences add to this complexity.
Comments	Service utilization: most measured primary outcome and is often used as a proxy measure for health care access.

	Healthcare Accessibility conceptual framework: perspective on access to health care Five dimensions of access and associated barriers to hospice and PC • Approachability ○ Messaging and outreach ○ Health literacy considerations • Acceptability ○ Social/cultural values and norms ○ Political perspectives • Availability ○ Geographic location, accommodations ○ Provider level of familiarity with resources • Affordability: ○ Household income ○ Healthcare insurance benefits • Appropriateness ○ Coordination of care ○ Quality of care

Nordly et al., Home-based specialised palliative care in patients with advanced cancer: a systematic review, 2016[23]	
Type + number of included studies	N= 8 studies (n=6 observational studies, n= 2 interventional studies), search 2000-2015
Type of participants (+ setting)	Patients with advanced cancer Patients were considered to have advanced cancer if the cancer was metastatic or incurable, or if patients were judged to have a short life expectancy
Intervention vs comparator	Home-based specialised palliative care (SPC) The composition of the SPC team had to include at least a doctor or a nurse.
Primary outcomes	**Place of death** • Forty-four to 90% of the patients who received home-based SPC died at home
Secondary outcomes	**Description of home-based SPC:** see table 3 in review

Table 3. *Home-based SPC service*

Author	Service denomination	Healthcare professionals	Capacity	Specialized education/ training	Reason for referral	Public or private
Ahlner-Elmqvist et al. (2004)	Hospital-based advanced home care	Multidisciplinary: nurses, oncologists, physiotherapist and social workers	25 home care patients 24 hours per day, 7 days a week	Yes	–	Public
Leppert et al. (2014)	Home care	Physicians and nurses	–	–	–	Public[b]
Gyllenhammar et al. (2003)	Palliative home care	Multidisciplinary	24 hours a day, 7 days a week	–	29% Social issues 33 % Combination of social problems and physical symptoms	Public[b]
Tiernan et al. (2002)	Home care team	Multidisciplinary	550 new in- and outpatients per year	–	–	Public–private founded[b]
Mercadante et al. (2011)	Palliative home care team	Physicians and nurses	–	–	–	Public[b]
Peters & Sellick (2006)	Home-based palliative care	Nurses[a]	–	–	–	Public[b]
Abela (2009)	Community palliative care team	Physicians and nurses[a]	–	–	44.6% Support 5.4% Palliative care 14.3% Equipment 21.4% Equipment & support 1.8% Palliative care & equipment 5.4% Uncontrolled symptoms 7.2% Other/unknown	Public –private founded[b]
Heedman & Strang (2001)	Hospital-based home care	Multidisciplinary	24 hours per day, 7 days a week	–	–	Public[b]

– = information not available; a = only team members mentioned in articles, there might be more healthcare professionals involved; b = judged public or private by the authors of the present review.

Source: retrieved from Nordly et al. 2016

Authors' conclusion (+ discussion)	There is a lack of controlled clinical trials and organisational descriptions regarding home-based SPC for patients with advanced cancer, resulting in poor information and a lack of evidence. Generally, home-based SPC seems to have some positive effect on pain and dyspnoea, but more high-quality studies are required.
Comments	Other outcomes, such as survival time, quality of life, performance status and symptom management are not reported in this evidence table.

Ogi et al., Community access to palliative care medicines – patient and professional experience: systematic review and narrative synthesis, 2021[17]	
Type + number of included studies	N=10 studies (n= 5 quantitative studies, n= 4 qualitative studies, n= 1 mixed methods study), search 2006-2019
Type of participants (+ setting)	Adults' patients in last year of life living in the community, in UK, Ireland, USA, Australia, Japan
Intervention vs comparator	experiences and outcomes of medicine access for patients and informal caregivers receiving community-based models of palliative care, during the last year of life
Primary outcomes	**Medicine access in community pharmacy services:** • Some pharmacies provide enhanced or commissioned palliative medicine services (keeping a core stock of palliative medicines and extended opening hours for access) • Patients and informal caregivers saw pharmacist as a source of medicine information (as well as GPs) if they had a relationship with them. • Lack of pharmacy stock of palliative care medicines (across all 6 studies): problematic stock, patients had to travel to more than one pharmacy before accessing medicine, reported delays in being able to provide palliative care medicines (even the pharmacies that were part of an enhanced commissioned service and specialist network) • Lack of information provision: (across 3 studies) little contact with community pharmacist , poor overall knowledge of services (patients often acquiring knowledge in an unplanned way through family/friends or when in a crisis situation), patients and informal caregivers wanted a more proactive role from pharmacists regarding prescription and supply processes of controlled drugs or when a new medicine was prescribed, inadequate provision of information to manage their medications at home appropriately, pharmacists reported lack of information about the patient (disease status, awareness of illness and opioids), lack of room for private counselling • Influences on accessing medicines: (across 4 studies) problematic communication with pharmacy causing delays in supplying medicines through a mismatch between prescriptions received and stocks held and/or lack of information on palliative care status of the patient (due to unfamiliar patients who had been referred by another network pharmacist or health professionals' reluctance to share information), health professionals' lack of knowledge about enhanced or commissioned services, lack of awareness of more general pharmacy services, disrupted communication when patients transferred between secondary and primary care settings affecting prescriptions and the ability to swiftly supply medicines needed. Facilitators: better training of counter staff, pre-emptive communication from community nurses about medicines likely to be required by patients, being part of a network of pharmacists where medicines and advice could be accessed • Practical problems with palliative medicine stock and couriering medicines: secure storage space, wide range of opioid dosage requirements for individual patients, delays in accessing stock, medicines not being on state reimbursement schemes, no one to courier prescriptions/ medication to and from GP, pharmacy and patient, a financial burden for some patients when delivery was not free of charge. • Outcomes: median time for accessing urgent palliative care medicines was significantly longer for non-commissioned services pharmacist's vs commissioned pharmacists to hold stock of palliative care medicines (5 hours vs 10 min) **Medicine access through GPs (family doctors)** • Most cited factors causing delay: (n=1 study) the need to clarify the advice given by the home care team, inability of someone to collect the prescription, the patients being unable to attend the surgery **Community specialist nurse independent prescribers**

	• most significant perceived benefit of nurse prescribing, reported by all six nurses, was that it enabled patients to access medication quickly, particularly near the end of their life, leading to effective symptom management + no need to call an out-of-hours doctor to prescribe (preventing delays) (n=1 study) **Hospice emergency medication kits** • HEMKs are typically ordered by a physician on referral to home hospice service, and kept in the patient's home, to allow the patient access to small quantities of medication that can be administered immediately on nurse instruction. Emergency medication kits contain sufficient medications for 12–72hours, thus avoiding the immediate need for pharmacy and physician involvement after hours. • Outcomes (n=3 studies): kits averted use of other services (an emergency department visit or hospitalisation was avoided by having a kit in the home), increased both patient and nurse satisfaction, the after-hours nurses perceived caller (patient/family) satisfaction was significantly higher in hospice patients with a kit compared with both the non-kit hospice patients and the HEMK hospice patients without a kit, more patients with kits received symptom relief within 30min vs without kits
Secondary outcomes	**Different service delivery models:** community pharmacy (n=4 studies), hospice emergency medication kits (HEMKs in the home (n=3 studies), specialist community nurse prescribers (n=1 study), general practice (n=1 study), and multiple service delivery components (n=1 study)
Authors' conclusion (+ discussion)	This review found sparse research in this area: 9 of the 10 studies were small-scale or pilot studies and local samples. Overall findings suggest there are problems with accessing medicines via community pharmacies, and several issues delaying access have been identified, many of which focus on either pharmacy stock or communication between the pharmacy and health professionals, and with patients. In our review we found pharmacies commissioned to provide stocks of locally agreed palliative medication lists reduced delays in medicine access and tailored lists produced through communication between pharmacies and GPs worked similarly. To address the communication gap between community pharmacy and the wider healthcare team, greater integration of the pharmacist into the primary healthcare team would be advantageous. Community palliative care specialist nurse prescribers were also reported to provide out-of-hours support and quicker medicine access in times of crisis.
Comments	Definition of medicine access: prescribing, dispensing, supplying, and providing associated information about medicines

Parajuli et al., Barriers to palliative and hospice care utilization in older adults with cancer: a systematic review, 2020[51]	
Type + number of included studies	Quantitative studies (retrospective designs) (n=18), mixed methods (n=1) Total of n= 19 studies, search up to 2018
Type of participants (+ setting)	Older adults (>65 years) with cancer, US, Canada, the Netherlands
Intervention (vs comparator)	Barriers to palliative and hospice care utilization
Primary outcomes	Major predictors of hospice/palliative care use: age, gender, race, marital status, socio-economic status, geographic residence, health insurance **Socio-demographic barriers** • Age:

	○ advanced age served as barrier to palliative or hospice care enrolment. ○ conflicting evidence: older adults were less likely to use palliative/hospice care compared to younger counterparts vs older patients with cancer more likely to use palliative/hospice care services than younger patients vs no significant association between age and use of PC services. • Gender ○ Males: less likely to utilize hospice care services compared to women • Race ○ Most studies (n=10): racial minority (i.e., Black, Asian, Pacific Islanders) less likely to use HC services compared to White ○ One study: racial minority greater odds of receiving PC. ○ Two studies: no significant association between race/ethnicity and PC/HC utilization • Marital status ○ Most studies (n=6): unmarried individuals less likely to use PC/HC services compared to married ones ○ In 2 studies: no significant association between marital status and PC/HC utilization • Socio-economic status (SES) ○ Patients with low SES: less likely to use HC. ○ Patients with lower educational level: less likely to use PC/HC • Geographical residence ○ Patients living in rural areas: less likely to use PC/HC services compared to urban/metro areas, mostly due to distance to facilities and access to those services. **Provider-related barriers** • Not feeling connected to their professionals hindered patient involvement or participation in decision making processes and influenced communication. • Feeling not being taken seriously by their professionals • Feeling that they were not informed enough about available care choices (e.g., hospice transfer) or treatment options (e.g. palliative focused treatments) for their condition
Secondary outcomes	**Health insurance-related barriers** • Proportion of HC recipients were lower among fee-for-service insurance compared to those enrolled in managed care. • Patients enrolled in other types of health insurance (Medicaid, private insurance) less likely to receive palliative care compared to patients with Medicare
Authors' conclusion (+ in discussion)	This systematic review identified various socio-demographic, provider-related and health insurance related barriers to palliative and hospice acre utilization among older adults with cancer. Patient-related barriers can guide the identification of at-risk population for underutilization of hospice and palliative care. Interventions are needed to address provider-related barriers such as communication challenges.
Comments	/

Parajuli et al., A systematic review on barriers to palliative care in oncology, 2021[51]	
Type + number of included studies	Quantitative studies (n=8), qualitative studies (n=18), mixed methods (n=3), search up to 2020
Type of participants (+ setting)	Persons with cancer and their families and/or oncology clinicians, studies conducted in US, Australia, Belgium, Europe, Canada, Germany, Japan, India, Iran, Türkiye, Columbia, France
Intervention (vs comparator)	Barriers to palliative care utilization and referral in oncology
Primary outcomes	**Barriers related to patient and family** • Negative image/stereotype of PC ○ Lacked knowledge and awareness about PC, about their disease trajectory. ○ Felt stigmatized by their communities following the cancer diagnosis. ○ Believed that PC required forgoing cancer therapy and equated PC with EOL care. ○ Reported that physicians described PC as main management services and did not discuss or refer them to PC services. ○ Reported experiencing communication barriers with physicians which hindered their understanding of the disease. • Denial of terminal nature of the disease/unrealistic expectations ○ Patients and family's denial of the terminal nature of the disease, unwillingness to stop anticancer therapy, request to not be referred to PC. ○ Families did not want to disclose to the patient about the diagnosis, so that the patient would continue to fight the disease if the diagnosis was not known. • Economic and logistic barriers ○ High expenses, lack of adequate healthcare insurance coverage, financial concerns due to an increase in out-of-pocket spending ○ Lack of PC professionals in the community, lack of time and difficulty in transportation, long wait times ○ Lack of time during consultation to discuss or ask question about diagnosis/prognosis and to make informed decisions. **Barriers related to healthcare system or policy**** • Organisational/structural barriers ○ Lack of availability or timely access to PC in community, PC specialist and services, outpatients PC programs, inpatients beds or resources to take referrals. ○ PC programs located in inconvenient locations, lack of private space/room for meeting with patients and/or families. ○ Lack of in-service training in PC, unclear job description of the PC team, lack of a standard formal educational curriculum on PC, lack of clear guidelines/protocols on timing of PC referrals, preference of health systems towards curative treatments with very little attention to PC ○ Institutional barriers: Excessive demand, inadequate numbers of physicians/health professionals and allied health support, health system hierarchy (senior medical officer needed for PC referral), wait times for PC appointments, poor infrastructure, lack of needed supplies, lack of institutional readiness and support for palliative treatments. • Administrative barriers/fragmentation of services

	○ Lack of advance directives and surrogate decision makers, continuity of care during transition, recognition among staff of the importance of optimal EOL care, available time due to high rate of consultations or heavy workload of oncologists, opportunities for support after highly emotional discussions, an adequate patient referral system due to structural problems ○ Procedures and authorizations required to access to medications, appointments, procedures etc, fragmentation of services and lack of coordination, unclear pathways, and triggers for PC referral. • Social and geographical barrier ○ Lack of knowledge on components and implementation of PC, lack of adequate centres providing PC, cultural traditions/beliefs regarding PC, lack of training, specialization, or higher education programs about PC ○ Lack of access to PC in rural area healthcare systems since most specialised cancer centres are in urban areas. • Healthcare cost/health insurance ○ Insurance co-payments, policy, reimbursement issues due to inadequate insurance coverage, expensive hospital bills, prospective payment systems of PC services and lack of financial resources for accessing PC
Secondary outcomes	**Barriers related to professionals* (clinicians/healthcare professionals)** • Negative stereotypes about PC • Patients and families' unrealistic expectations • Professionals' lack of knowledge, education, and training on PC • Difficulty prognostication/appropriate timing to introduce PC. • Clinicians' own unrealistic expectation about patient's prognosis. • Communication barriers • Role confusion
Authors' conclusion (in discussion)	Professionals: • It is important to include PC education and training in medical school curriculum. • The term palliative care was itself considered as a barrier to PC referral. Suggestion to reframe and better explain to patient and family, to use synonymous terms such as 'supportive care,' 'comfort care.' Patients and families: • The need for educational interventions to educate the public and raise awareness of PC and its components, its benefits, and its availability. Health system: • Shortage of PC specialists and trained professionals to address the demands of people requiring PC services is a huge barrier that applies not only to individuals with cancer but to all serious illnesses. • To increase the number of outpatient PC services, this will lead to earlier access to PC and will maintain continuity of care. Conclusion: The identified barriers can guide interventions development to improve access, utilization and referral practices related to PC.

Comments	*Results on barriers perceived by professionals only shortly presented more details in results in review ** It is unclear by whom the barriers related to healthcare system were reported. No clear distinction was made between palliative care and EOL care.

Procter et al., A review of the literature on family decision-making at end-of-life precipitating hospital admission, 2019[53]	
Type + number of included studies	Qualitative studies (n=7), quantitative studies (n= 4), mixed methods (n=1), case note review (n=1) (total n=13), search 2008-2018
Type of participants (+ setting)	Non-cancer adult patients who had expressed a preference to die at home, family informal caregivers and relatives, clinicians, UK, US, New Zealand, the Netherlands, Belgium, Canada
Intervention (vs comparator)	Factors precipitating admission to hospital in the last few hours of days of life
Primary outcomes	**Patient and family decision-making** • A study showed that majority of patients (76%) requested themselves an EOL hospitalisation. Reasons: they felt safer in hospital, wanted to be treated in hospital, still hopeful of prolonging their life, hospital was considered as a safer place where they would receive the right treatment and care to sustain life. • Aspects influencing family decisions for hospital admission: ○ the informal caregivers' emotional and physical ability to cope and to provide the care needed, also determined by their lack of knowledge, practical experience and skills required to look after the patient. ○ lack of availability of equipment to support families to care for patients at EOL + lack of integrated out-of-hours GP services. ○ multiple and conflicting caring roles by informal caregivers: hospitalisation so they could attend to other caring responsibilities. ○ deteriorating symptoms (e.g., breathlessness): transition to hospital twice as likely ○ increase in physical care needs related to activities of daily living. ○ type of patients: majority of cancer patients knew they were dying vs only half of patients with non-malignant conditions were aware that they were dying and were less likely to die at home or in their place of preference. ○ less likely to request EOL hospital admissions by family members if they had explored EOL preferences and future care plans with a health professional
Secondary outcomes	**Communicating end-of-life care needs with patients and families** • (lack of) discussions about EOL, determined by ○ lack of information about possible outcomes of care (including knowledge that the patient was 'sick enough to die') ○ prognostic uncertainty often poorly communicated, often cloaked in confusing euphemisms, or families left in unwanted false hope or incongruence between message and aggressive level of provided care. ○ a shift in mindset needed away from expectations of cure towards an acceptance of EOL: needs time to evolve. If shift in mindset did not happen, family doctors preferred hospital admission as appropriate response to patients' situation.

	○ opportunities to discuss EOL preferences and plan with a palliative care professional often not made available to patients and families. ○ proactive communication by GPs often did not take place due to: doctors found it difficult to find the right moment to talk about dying (in particular in fast deterioration, patients who still seemed active and not very ill, or patients who are deteriorating slowly) ○ preference of GPs for patients with distressing symptoms to be managed better in hospital. ○ reticence among family members to discuss the condition and needs of the patient + denial that patient could die (need for more prognostic information about death)
Authors' conclusion (+ in discussion)	Barriers experienced by people with non-cancer conditions nearing death that inhibit transition to end-of-life care: hopeful optimism that repeated hospital admission can prolong life, prognostic uncertainty which makes it difficult for GPs to know when to discuss EOL care, time required for patients and informal caregivers to transition between first conversations and acceptance of the situation. Transition to EOL care framework often made too late to benefit from hospice care: support needed for patients, their informal caregivers, and clinicians through the uncertainty of a deteriorating condition trajectory (a role for hospices in providing education and support for GPs)
Comments	/

Raine et al., A narrative literature review on human resource planning for palliative care personnel, 2020[42]	
Type + number of included studies	N=13 studies, search date not reported
Type of participants (+ setting)	
Intervention vs comparator	Human resource planning
Primary outcomes	Factors influencing the supply of hospice and palliative care professionals. - lack of appropriate training opportunities for professionals who desire to work in hospice and palliative care: not due to lack of fellowship opportunities, but development of interest later in their careers. A mid-career training program would be a good solution. - Among nurses, there are also limited training opportunities to work in hospice and palliative care and much of the existing training comes on the job either formally or informally. - high rates of turnover in hospice and palliative care professionals probably due to lack of training, high-stress, sicker and vacation time taken. - many hospice and palliative care physicians work only part time in that specialty. Those planning for hospice and palliative care staffing must ensure that enough individuals are properly trained to provide services on a part-time basis. Factors influencing the demand for hospice and palliative care professionals. - While originally conceived of as a service only for those very near the end of life, as the specialty grows, hospice and palliative care professionals are being asked to become involved in care at earlier stages to control pain and manage symptoms.

	- hospice and palliative care are practiced differently in different regions, settings, and among different teams. The makeup of an interprofessional palliative care team is rarely the same in different programs. - variation in structures: residential hospice, community hospice, hospital inpatient, hospital consult are among the different ways in which hospice and palliative care is provided. The variation in setting, program structure, and staffing structure means there is also a great deal of variation in the number of patients, a team can see per FTE. - the experience level of the professionals on the team has been shown to make a difference in the efficiency of the team
Secondary outcomes	/
Authors' conclusion (+ discussion)	It is important that those in charge of planning for end-of-life care recognize that the widening scope of palliative care and the aging population offer no let-up in the gap between the supply and demand for hospice and palliative care. The literature provides several recommendations for the best way to reduce the gap between the supply and demand of palliative care professionals. Those that make recommendation for a solution seem to fall within three general categories: - Train more primary caregivers and those in other specialties to perform basic hospice and palliative care. - Make changes to the system to increase efficiency. - Allow for mid-career specialist training
Comments	/

Salamanca-Balen et al., The costs, resource use and cost-effectiveness of clinical nurse specialist-led interventions for patients with palliative care needs: a systematic review of international evidence, 2018[37]	
Type + number of included studies	N= 79 studies (n= 37 RCTs, n= 22 quasi-experimental studies, n= 7 service evaluations, n= 13 economic analyses), search up to 2015
Type of participants (+ setting)	patients with palliative care needs, defined as seriously ill patients and those with advanced disease or frailty who are unlikely to be cured, recover, or stabilize, US, UK
Intervention vs comparator	Clinical Nurse Specialists (CNSs): nurses who have additional education, preferably at degree level or beyond. definition: a nurse prepared beyond the level of a nurse generalist and authorized to practice with advanced expertise in a nursing field. Specialist practice includes clinical, teaching, administration, research, and consultant roles. CNSs frequently work as part of multidisciplinary groups; this makes it difficult to evaluate their effectiveness as individual provider.
Primary outcomes	**Healthcare utilisation** • RCTs: ○ (n= 17) no significant difference between groups in terms of LOS, emergency department (ED) visits, number of days in the ICU, medication use or readmissions ○ (n=13) CNS-led interventions were effective in reducing specific economic outcomes: reduction in doctors' visits (GP or specialist visits) (n=4), reductions in ED visits (n=2), reductions in hospital readmissions (n=5) and reductions in LOS (n=7), effective at increasing the use or prescription of medications (n=2) • Quasi-experimental studies

	○ reduction in readmissions (in 10 of 17 studies), reduction in LoS (in 8 of 13 studies), increase in GP visits to the long-term care facilities and reduction of transfers to hospital (n= 1), increased prescription and use of medications (n=2) • Service evaluation studies ○ Significant reduction in re-hospitalizations (in 4 of 7 studies), increase in prescription of medications (n=1), enhanced chemotherapy treatment completion and reduction on treatment dose deviations (n=1) **Costs** • RCTs: ○ less expensive than usual care in 4 out of 20 studies reporting costs. ○ 2 of the 20 studies reporting costs found that CNS interventions were more expensive, although in each case, the potential for cost-effectiveness was noted due to other positive outcomes. ○ 14 studies found non-significant or inconclusive results regarding costs. • Quasi-experimental studies ○ In 3 of 13 studies: reduction is costs of care. ○ More expensive compared to control group (n=1) • Service evaluation studies ○ Reduction in hospital ad direct readmission costs (n=2) **Cost-effectiveness** • clear evidence of cost-effectiveness or improvement on health economic outcomes (in 7 of 13 studies) • In four studies, cost-effectiveness was not demonstrated mainly because of methodological challenges. • The remaining two studies: the interventions were associated with higher costs compared to usual care although some patients preferred these care models.
Secondary outcomes	**Characteristics of the interventions**

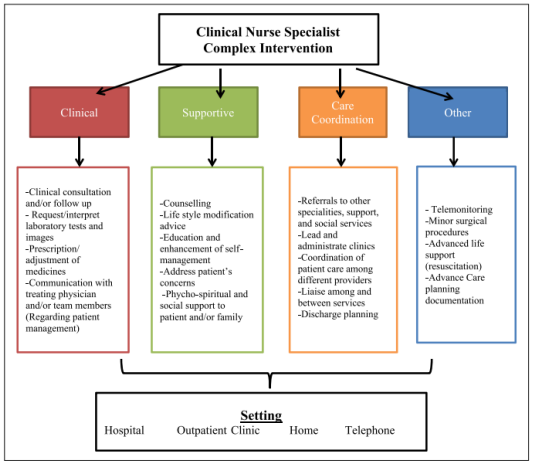


Figure 3. Components of Clinical Nurse Specialist interventions.

Source: retrieved from Salamanca-Balen et al.,2018

- In general, interventions were complex and involved multiple interacting components.
- Interventions in which the clinical component was predominant included activities directed to the diagnosis, treatment and control of the disease and were performed in hospitals, outpatient clinics or patients' homes.
- Supportive interventions: they sought to increase patients' knowledge about their disease and its management, and at the same time aimed to give psychological/spiritual support.
- Care coordination activities
- a wide range of activities were reported, including clinical consultations (in hospitals, at home, specialist clinics or via the telephone), the request of follow-up investigations, prescription or adjustment of medications, referrals to other agencies or staff, provision of support directed at overall well-being, and education to enhance self-management, as well as administrative work and liaison and communication with other professionals

Authors' conclusion (+ discussion)	Clinical Nurse Specialist interventions may be effective in reducing specific resource use such as hospitalizations/rehospitalizations/admissions, length of stay and health care costs. There is mixed evidence regarding their cost-effectiveness. There is evidence that CNS interventions may be effective in reducing hospitalizations and/or readmissions (20 out of 46 papers showed statically significant reductions in this outcome, while the remaining 26 did not report significant levels or reported non-significant results). LOS was significantly reduced in 17 out of 33 studies, and only 1 study showed that the intervention significantly increases LOS. The rest of the papers (15 out of 33) reported no significant levels, or it was not clear. There is insufficient evidence to demonstrate that CNS interventions lower days in the UCI or ED visits. Four studies reported UCI days, all of which showed non-significant changes between groups. Regarding ED visits, only 3 out of 16 studies found that intervention group significantly reduced this outcome, while the remaining 13 showed no significant changes. There was some evidence about referrals (e.g. to other health care professionals, health services or clinics). Of 11 studies, 7 were inconclusive (showing

	non-significant differences or not reporting significant levels. In contrast, four studies reported significant differences regarding referrals. Medication prescriptions were significantly increased in the intervention group in two studies, and medication uptake/use by patients was raised in another three studies.
Comments	/

Sellars et al., Perspectives of people with dementia and informal caregivers on advance care planning and end-of-life care: a systematic review and thematic synthesis of qualitative studies, 2019[54]	
Type + number of included studies	Total n= 84 studies, search up to 2018, thematic analysis
Type of participants (+ setting)	Adult people diagnosed with dementia of any type or stage in the illness trajectory, and/or informal caregivers (i.e., family member, friend, or other appointed substitute decision-maker) who provided unpaid care and support to a person with dementia, US, UK, Europe, Australia, Canada, Asia
Intervention vs comparator	Perspectives of people with dementia and their informal caregivers concerning ACP and end-of-life care in dementia
Primary outcomes	**Avoiding dehumanising treatment and care** • remaining connected ○ a need for social, sensory, and spiritual engagement (attending to the 'true self') consistent with a 'normal life' without dementia. ○ important to continue to participate in recreational activities, spend time with family and be treated as an individual with a unique personality. ○ having nursing staff physically present and verbally communicative with their dying relative, had informal caregivers inspired their trust and relived anxiety. • delaying institutionalisation ○ perceived 'robbed' dignity of care, ACP preferences deliberately ignored by care staff or were not prioritised within these services. ○ some informal caregivers decided to keep the person with dementia at home as long as possible to avoid 'humiliating' acts of care. ○ dignified care within institutions= having preferences known and adhered to by health professionals, maintaining a respectable physical appearance, having privacy, being clothed, having hygiene maintained, being comfortable, being able to use the toilet and been free of fear and pain • rejecting the burdens of futile treatment ○ informal caregivers who participated in ACP focused more on a 'good death' (in line with the preferences of the person with dementia), believed that aggressive treatment caused only prolonged suffering and were preferring 'to let nature takes its course', to have a 'natural death without machines'. ○ informal caregivers who did not participate in ACP: struggled to understand dementia's dying process and felt obliged to treat what could be treated (e.g., pneumonia) **Confronting emotionally difficult conversations**

- signifying death
  - some informal caregivers felt unable to discuss AD because: it would cause the person to 'feel they were dying', too harsh or inhumane to set goals or document ACP preferences, might be perceived as 'putting the person with dementia to their death'.
- unpreparedness to face impending cognitive decline
  - some informal caregivers and patients made an active decision not to participate in ACP (too 'frightening' to think about in advance), or 'no real urgency' for ACP and avoided the discussion.
  - other informal caregivers regretted they had not completed ACP earlier (patient no able anymore to participate in the decision-making process)
- locked into a pathway
  - completing ACP documentation was perceived as a barrier to autonomy and locked the person in a 'static and immutable' contract, the pathway already predefined by health professionals.
  - some preferred to make informal ACP plans.
  - other informal caregivers and patients felt reassured because they perceived ACP documentation could be revised later of preferences changed.

Navigating existential tensions

- accepting inevitable incapacity and death
  - informal caregivers and patients who were more accepting progressive, irreversible and terminal nature of dementia: better able to engage in ACP discussion.
  - ACP assisted by preparing them for death and by enabling them to feel more comfortable making EOL treatment decisions (regarding resuscitation and artificial nourishment)
  - Lack of communication with health professionals implicitly reinforced belief that death should remain unspoken.
  - Need to have supportive health professionals who encouraged discussion of death, for acceptance of death.
- fear of being responsible for cause of death
  - even when ACP has occurred, operationalising goals for comfort into actions, which would lead to person's death: informal caregivers became less able to follow the preferences as they felt responsible for 'killing' the person, too overwhelming, to ignore the preferences of the person to preserve their own peace of mind and maintain a clear 'conscience'.
- alleviating decisional responsibility
  - ACP helped to overcome the perceived guilt and 'burden' that they believed they would have otherwise experienced during EOL decision-making.
  - Their responsibility was simply to 'implement decisions' or to 'fulfil the patient's wishes'.

Defining personal autonomy

- struggling with unknown preferences
  - informal caregivers confronted by a 'moral dilemma' when medical decision was required and ACP plan was not made, relied on their knowledge and sense of who the patient was before the onset of dementia, feelings of ambivalence and guilt and left them to hope that they were doing the 'right thing'.
  - spousal informal caregivers more implicit understanding of patient preferences but more difficult for informal caregivers who shared less frequent contact.

	• depending on carer advocacy ○ patients expected their informal caregivers to be present during medical decisions, to protect and enforce their EOL preferences. ○ informal caregivers felt it was their duty to ensure preferences were adhered to, they anticipated that they might 'have to fight the doctors' to prevent unwanted interventions. • justifying treatments for health deteriorations ○ informal caregivers felt they needed to 'breach' the preferences to save them from a 'premature' death. Some health events (e.g., colds, bone fracture) appeared to discount the life-threatening nature of such episodes in dementia, enables the patient to return to their previous state of health. **Lack of confidence in healthcare settings** • distrusting clinicians' mastery and knowledge ○ some informal caregivers perceived 'medical uncertainty' among healthcare professionals, leading them to feel frustrated and lose trust in healthcare professionals. ○ some believed that physicians lacked confidence in making clinical judgements and ACP process or had actively 'ignored" the carer's concerns. ○ other informal caregivers considered healthcare professionals as 'specialists' of dementia and chose not to 'question clinicians' decisions or actions about care'. • making uninformed choices ○ some informal caregivers completed ACP on behalf of non-competent patient felt that they had not made the best ACP plan, not enough time or received not enough support from clinicians to explore all options, they could have 'come up with a better plan' if they were better informed of the course of dementia and the treatment options. ○ informal caregivers and patients expressed a need for 'better education' around the course of dementia and medical decisions + ongoing communication and revisited to allow time to digest the relevant information. • deprived of hospice access and support at end-of-life ○ informal caregivers: disappointed by difficulties they experienced 'getting through the front lines' and accessing hospice and support. They believed it was a result of limited care options, high cost of services and inconsistent/lack of communication from healthcare professionals. ○ informal caregivers felt 'cheated' because hospice care was not offered until too late. ○ informal caregivers felt overwhelmed when patient was discharged or 'kicked out of hospice' because 'not dying fast enough' to qualify for HC. ○ The provision and duration of hospice access was inadequate, and informal caregivers questioned appropriateness of using 'EOL care' model in dementia given its unpredictable disease trajectory
Secondary outcomes	/
Authors' conclusion (+ in discussion)	Themes identified in this review, such as avoiding dehumanising treatment and care and defining personal autonomy, emphasise person-centred care as a central goal and priority of dementia care. The experience of ACP and EOL care was characterised by a sense of uncertainty in decision-making. ACP required some to confront emotionally difficult conversations and some informal caregivers felt unprepared in being able to adhere to ACP preferences and make EOL decisions on behalf of the person with dementia.

	Advance care planning strategies that attend to people's uncertainty in decision-making may help to empower people with dementia and informal caregivers and strengthen person-centred care.
Comments	See scheme (figure 2) for relations between main themes ACP was defined as any intervention aimed at supporting people to consider and communicate their current and future treatment goals in the context of their own preferences and values. End-of-life care was defined as any treatment or care around death or the dying process.

Senderovich et al., Integrated palliative care and health care delivery among older adults, 2020[34]	
Type + number of included studies	N= 15 studies (RCTs), search 2000-2020
Type of participants (+ setting)	aged population, 65 years and older, US, Europe, China
Intervention vs comparator	Early integration of PC vs traditional PC
Primary outcomes	**HC utilization:** - Integrative PC approach: fewer emergency room visits, reductions in hospitalizations and re-admissions, shorter overall hospital stay, and a significant decrease in ICU length of stay for referred patients ($p < .001$), all without a significant increase in mortality ($p = .09$) (n=3 studies) **Costs** - Most studies proved integrated PC to be cost-effective by significantly reducing end-of-life care costs incurred in hospitals (n=1 study). One study, however, noted that although PC is very effective, integration may lead to increased total inpatient spending, as county hospitals are required rather than town hospitals for the provision of PC services.
Secondary outcomes	Patient-related outcomes were also reported but not presented in this evidence table.
Authors' conclusion (+ discussion)	A reduction in unnecessary hospitalizations, shortened overall hospital stay, decreased stay in an intensive care unit (ICU), along with decreased caregiver burden has also been shown in studies. Effective coordination of care is crucial in the prevention of fragmented care and in ensuring the expressed wishes of patients are honoured. Furthermore, the stigma attached to the provision of PC is largely due to inadequate knowledge about PC and hence, education is key
Comments	/

Sezgin et al., Transitional palliative care interventions for older adults with advanced non-malignant diseases and frailty: a systematic review, 2020[36]	
Type + number of included studies	N= 6 studies, search 2002-2019
Type of participants (+ setting)	older adults with non-malignant chronic diseases and complex conditions, US, UK, Hong Kong
Intervention vs comparator	Intermediate care or transitional care vs usual care
Primary outcomes	**Healthcare system related outcomes** • **Readmissions** (n=4 studies): Most of the studies reported significant decreases in readmissions • **Length of stay** (n= 1 study): reduced inpatient stays • **ED visits** (n= 2 studies): unclear evidence: no significant reduction
Secondary outcomes	**Patient-related outcomes were also reported but not presented in this evidence table.** **Characteristics of the interventions** - Delivered by interdisciplinary teams. - technology-assisted interventions, including electronic health records and telephone calls. - implemented pre and post discharge transitional care, while two studies delivered post-discharge follow-up with home visits.
Authors' conclusion (+ discussion)	Overall, TPC interventions were associated with lower readmission rates and LOS, improved quality of life and better decision-making concerning hospice care among families. Outcomes for ED visits were unclear. Although studies reported an impact on healthcare utilisation including reduced LOS and readmission, there was insufficient evidence that TPC decreased ED attendances. Specifically, specialist-delivered pre- and post-discharge assessments and follow-up interventions did not reduce the mean number of ED attendances. This may relate to the inability of TPC to address unexpected crisis, where urgent assessment in ED is appropriate. However, as only two studies assessed this outcome, there is a need for further research in this area. Pre and post discharge TPC interventions implementing strategies to improve communication between care professionals. Relevant and accessible information has been highlighted as a key factor in patient's transition to palliative care. Other important factors include agreement, timing, and decision making amongst staff members. According to a systematic review, the main problems with access to palliative care are lack of knowledge and education amongst health and social care professionals, and a lack of standardised referral criteria.
Comments	/

Shepperd et al., Hospital at home: home-based end-of-life care, 2021[25]	
Type + number of included studies	N= 4 RCTs, search up to 2020, Cochrane review
Type of participants (+ setting)	people aged 18 years and older, Norway, US, UK
Intervention vs comparator	EOL home-based care vs hospital or hospice care End-of-life care at home is the provision of a service that provides active treatment for continuous periods of time by healthcare professionals in the patient's home for patients who would otherwise require hospital or hospice inpatient end-of-life care
Primary outcomes	**Place of death** • Home-based end-of-life care increased the likelihood of dying at home compared with usual care (n= 2 studies) **(unplanned) Admissions to hospital** • Admission to hospital while receiving home-based end-of-life care varied among trials (n= 3 studies): increase vs reduction **Costs** • The effect of home-based end-of-life care on health service resource use and cost was uncertain (n= 2 studies): there was a reduction in total health service cost of 18-30% for participants receiving EOL care at home.
Secondary outcomes	**Components of home-based EOL care:** • In 3 of 4 studies: multidisciplinary care which included specialist palliative-care nurses, family physicians, palliative-care consultants, physiotherapists, occupational therapists, nutritionists, and social care workers. • One of the interventions was hospital-based at the Palliative Medicine Unit, which provided community outreach, including all inpatient and outpatient hospital services were provided at the unit unless care was required elsewhere for medical reasons, the unit served as a link to community services, and the PC physician and community nurse were defined as the main caregivers, predefined guidelines were used to keep optimal interaction between services, community professionals were offered an educational program that included bedside training and 6-12h of lectures every six month • Two trials described an educational component, either for participants and families on goals of care and expected course of disease and outcomes, or for community staff.
Authors' conclusion (+ discussion)	The evidence included in this review supports the use of home-based end-of-life care programmes for increasing the number of people who will die at home. The rationale for providing end-of-life care at home is complex as it reflects the policy objective of providing patients and their families with a choice of where and when they want care. One difficulty underpinning the concept of choice in this context is that while more people want to die at home, they also recognise the practical and emotional difficulties of exercising this choice. For example, terminally ill people express concern about being a 'burden' to family and friends and worry about their families seeing them in distress or having to get involved with intimate aspects of care. Similarly, although caregivers of terminally ill people often prefer to care for their relatives at home, continuity of care may be difficult to achieve, and yet it might be essential to fulfil the choice of dying at home.
Comments	Other outcomes, such as satisfaction, symptom control, caregiver outcomes, staff views are not reported in this evidence table.

Siouta et al., Integrated palliative care in Europe: a qualitative systematic literature review of empirically-tested models in cancer and chronic disease, 2016[30]	
Type + number of included studies	N= 14 studies (7 models for chronic disease, 4 for integrated care in oncology, 2 for both cancer and chronic disease and 2 for end-of-life pathways), search 1995-2013
Type of participants (+ setting)	Adult patients with advanced cancer/chronic disease in Europe
Intervention vs comparator	Integrated palliative care strategies (implementation of models, namely standardized designs that provide frameworks for the organisation of care for people with a progressive life-threatening illness and/or for their (in)formal caregivers)
Primary outcomes	Integrated care in oncology - collaboration between palliative medicine unit and community service (Norway): no difference in hospital utilisation - transmural home program between primary care team and supporting hospital care team (The Netherlands): less likely rehospitalisation, more likely home deaths. - clinical intervention of OC team and multidisciplinary decision-making (France): less likely deaths in hospital - integration of PC into regular internal ward services in general hospital (Germany): shorter LoS Models for chronic disease - Dementia (UK): assessment of PC needs: no organisational outcomes reported. - Multiple Sclerosis (UK): cost-effectives due to reducing inpatient and community costs. - HIV/AIDS (UK): more likely for homes deaths - Chronic heart Failure (UK): home-based PC: more likely to die in place of choice, reduced rehospitalizations. - Advanced chronic disease (Spain): interdisciplinary teamwork in a medium- and long-term hospital: no organisational outcomes reported. Models for cancer and chronic disease - Cambridge Hospital at Home for palliative care (CHAH, UK): more likely to stay at home in final 2 weeks, higher number of GP visits. - Integrated Plan of PC of the Autonomous Community of Madrid (Spain): decreased stay at PCU, more likely for home deaths, more likely for transfers to intermediate stay care centres. End-of-life pathways: withdrawn - Liverpool Care Pathway adapted for Italy. - Liverpool Care pathway adapted for The Netherlands - LCP in nursing homes
Secondary outcomes	The included studies employ three different collaboration strategies and their combinations: i) meetings of the team that is involved in the implementation of the model (model-responsible team), ii) meetings between the model-responsible team together with experts from other disciplines involved in the treatment of the patient, iii) utilization of predefined protocols. It is important to note that the collaboration is not necessarily related to the composition of the team. For example, a model-responsible team may be multi-disciplinary but still base its decisions on meetings where additional disciplines are represented. In other words, the principal difference between (i) and (ii) is the participation of experts that are not directly related to the implementation of the model in question on a frequent basis. This generic framework consists of the following aspects:

	- Focus of intervention: The focus of intervention will be placed on symptom treatment, consulting of patients/family and training of the personnel. - Setting: The design of the framework is such that it can be applied to every care setting. - Timing of intervention: The intervention can be initiated throughout the disease trajectory either concurrently or in the end-of-life. - Composition of team: The framework requires a multidisciplinary team with members that are trained in the delivery of PC. This team can consist of GPs, physician specialists, nurses and specialist nurses, psychologists, social workers, and administrative assistants. - Collaboration strategy: The collaboration strategy, which refers to the ways that the represented disciplines cooperate and assess emerging issues, should be based on the involvement of the multidisciplinary team and its meetings and the utilization of protocols. The proposed framework has a threefold focus: treatment, consulting, and training.
Authors' conclusion (+ discussion)	The results show a strong agreement on the benefits of the involvement of a PC multidisciplinary team: better symptom control, less caregiver burden, improvement in continuity and coordination of care, fewer admissions, cost effectiveness and patients dying in their preferred place. As regards effectiveness, all but one study, showed positive outcomes in terms of better symptom control and better quality of life, better communication between personnel, patients and caregiver, more deaths at the patients' homes and more cost-effective care. However, this result should be interpreted with care given the variability in the design of the interventions, some of which were not RCTs and therefore of lower quality.
Comments	/

Soltani et al., Economic evaluation of palliative care for patients with cancer disease: a systematic review, 2022[41]	
Type + number of included studies	N=29 studies, search 2000-2021
Type of participants (+ setting)	Cancer patients
Intervention vs comparator	Palliative care interventions vs usual care
Primary outcomes	Cost-effectiveness - inconclusive findings: most studies (26 out of 29 studies) concluded that palliative medicine interventions were cost-effective and yielded positive cost-effectiveness results. 20 studies confidently concluded about the costs and benefits of providing palliative care services on cost-effectiveness and cost savings, and 2 studies made such a conclusion with uncertainty. - Although palliative care intervention is cost-effective in some situations, there is a great deal of uncertainty about the decision to implement it. - In some cases, palliative medicine is cost-effective from the perspective of society and service professionals, but such interventions are not cost-effective from the patients' perspective due to the risk of using new treatments and the desire to receive definitive treatments.

	- A few studies have stated that palliative medicine intervention in cancer patients increases costs but have stated that the use of these methods will lead to improved treatment outcomes at the same time
Secondary outcomes	/
Authors' conclusion (+ discussion)	Palliative care is usually less expensive than comparator groups, and the cost difference is statistically significant in most cases, and this treatment is a relatively cost-effective option. However, making the right relevant decision and applying it as a dominant therapy approach in different countries requires further study in larger populations and over a longer period.
Comments	/

Spacey et al., Systematic critical realist review of interventions designed to improve end-of-life care in care homes, 2020[13]	
Type + number of included studies	N= 41 (n=5 parallel group design, n= 7 quasi-experimental designs, n= 1 randomized partial cross over design), search 2000-2018
Type of participants (+ setting)	Aged care residents, relatives, bereaved relatives, care home staff (including managers, registered nurses, care assistants), in UK, USA, Sweden, Ireland
Intervention vs comparator	Complex interventions aimed at supporting EOL care in care homes (nursing and residential care homes) *Hospices and hospitals excluded
Primary outcomes	**Objective outcomes** (number of ACP completed, place of death, number of unnecessary hospital admissions, cardiopulmonary resuscitation requests): no effect or conflicting evidence. • Immediate outcomes tended to report more positive outcomes than longer-term outcomes, with rarely established sustainability over time. • Multicomponent interventions tended to report more positive outcomes.
Secondary outcomes	**Intervention mechanisms**: all related to <u>education</u> (EOL discussion with residents and relatives and ACP; leadership and communication with external services; overarching principles such as person-centres and dignified EOL care; education on identifying the signs and symptoms of EOL; dementia education; symptom and pain management), often combined. • Majority of educational interventions were designed for registered nursing staff. • Education hypothesized as most effective mechanisms to address common issues associated with EOL care: lack of knowledge and confidence to engage in ACP; poor communication with residents with dementia due to staff's lack of knowledge of symptoms of dementia. • Fixed number of sessions or as an ongoing process (majority of studies with time-limited interventions) • Mode of education delivery appeared to influence the length: workshops, peer training, online modules, lectures, action learning, away days.

	• Many interventions had also additional mechanisms, to improve collaborations with external services (GP, hospice staff) via collaborative meetings; formalized reflective practice sessions; introduction of external professionals into care homes to help facilitate and support interventions (e.g. for training) **Contextual mechanisms:** • Resource and financial capabilities of care homes impacted on their ability to engage with interventions requiring extended time and resources. • Existing work schedules of care home staff impacted on sustainability: staff often had to create time to engage with the intervention→ lack of time was a common barrier to implementing and maintaining effective change. • Effectiveness of education sessions also not sustained when high staff turnover + when small size of workforce (knowledge lost when staff left care home) + only non-registered care home staff in care homes, who have increased reliance on GPs and registered nurses + lack of time of home managers to engage in the meetings. **Human agency:** • Care home staff often described as being passionate and engaged, driven by a desire to improve the experiences of families and residents receiving EOL care, a desire for self-improvement through knowledge and learning but variable level of cascade knowledge (too junior or at more senior level: lack of motivation, EOL care lower priority for care home managers) • Culture of dealing covertly with death and dying reduced staff's confidence to discuss death with residents + staff's personal background and experiences could influence their ability to discuss dying with residents and relatives (death as a taboo subject) • Conflict with relatives who were "not ready", "not accepting", "not understanding" about approaching death, and would not "give up". • Conflict with external services: e.g. out-of-hours GPs unwilling to cooperate due to negative attitudes towards care home staff (overrode their decisions + tendency to admit residents to hospital at EOL **Self-reported staff outcomes** • Self-proclaimed improvement in knowledge and confidence: positive tendency
Authors' conclusion (+ discussion)	In terms of outcomes, much of the current data are neither robust enough nor sufficiently longitudinal to draw conclusions out the effectiveness or sustainability of the interventions that have been developed. It was consistently found that high staff turnover and the limited resources of care homes impacted on the sustainability and embedding of change into practice. Specifically, education delivery, which was too demanding on resources and time, was often not sustained by care homes. However, these contextual barriers were generally only identified in studies evaluating outcomes over longer periods of time. Studies reporting on immediate outcomes following an intervention tended to report more positive outcomes
Comments	Critical realist terminology • Interventions mechanisms: The mechanisms contained in interventions that are designed to change the behaviour of those at whom they are targeted. • Contextual mechanisms: The resources and restrictions embedded in the social and organisational context that might inhibit or promote the effectiveness of intervention mechanisms. • Human agency: People's experiences and interpretations of, and responses to the intervention and contextual mechanisms

	• Outcome: The changes in behaviour that result from how people respond to the intervention and contextual mechanisms

Suntai et al., Access barrier in rural older adults' use of pain management and palliative care services: a systematic review, 2021[48]	
Type + number of included studies	Qualitative studies (n=4), mixed methods (n=1), quantitative studies (n=3)
Type of participants (+ setting)	Older adults (>60y) with any illness that indicated a need for pain treatment, palliative or hospice care, Canada, South Korea, Thailand, Uganda, Australia, US
Intervention (vs comparator)	Transportation-related barriers experienced by rural older adults in accessing pain and palliative care
Primary outcomes	**Lack of public transportation** • Lack of availability: e.g., operates 3 times or fewer per day. • Poor availability and access to public transportation is associated with isolation for older adults living in villages. **Lack of special needs/wheelchair accessible vehicles** • Traveling is a difficult activity for both the terminally ill and their family members: challenges they experienced helping their care recipients out of the car when they arrived in hospital, due to lack of mobility and lack of wheelchairs. • No accessible vans for transport because their community was too small for such services. **Lack of reliable drivers** • Delayed or missed hospital visits due to unpredictable driver status. • Moderated by socioeconomic status: lower income associated with higher unmet healthcare needs based on availability of a driver in the family. • Family members were often the only drivers, older adults without family members had small network of people that could help with driving. **High cost of transportation services** • Transportation third highest expenditures for rural families • In last month of life extensive travel to bigger, urban hospitals for medical appointments + very costly requiring expenses for hotels, meals, and parking **Poor road and weather conditions** • Bad weather and uneven roads + frail older adults experienced more pain which caused anxiety in the driver. **Remoteness to pain and palliative care services** • Limited choice for palliative care services because they were limited to the facility closest to them: they had to drive long distances, sought care outside of their community and had no choice on the location of their death. • EOL care often scattered across many places: specialty pain treatment often meant going to a large regional hospital
Secondary outcomes	/
Authors' conclusion (+ discussion)	Suggestions made by the authors to overcome the transportation barriers:

	• Collaboration between health professionals and elder service agencies, onsite medical services, and telehealth • Partnerships between medical service professionals and ride-share services • Setting up a peer-to-peer service to connect patients living in the same or nearby areas to share rides, providing gift cards/vouchers for ride services, having a community van that can transfer patients to and from appointments. • Accompanied by funding. Conclusion: Older adults residing in rural areas are more vulnerable due to resource poor community.
Comments	No differentiation made between PC and HC Some studies in developing countries.

Taylor et al., A scoping review of initiatives to reduce inappropriate or non-beneficial hospital admissions and bed days in people nearing the end of their life: much innovation, but limited supporting evidence, 2020[38]	
Type + number of included studies	N= 50 studies, search 2013-2018
Type of participants (+ setting)	Palliative care patients
Intervention vs comparator	palliative care initiatives Hospital utilisation was defined as admission to either hospital and/or emergency departments, whatever the cause, in patients considered to be in the last year of life
Primary outcomes	**Single point of access** (n=1 study, 24-h telephone SPA service in UK, with senior nurses ats the first points of access) • Place of death: 65% died at home, 11+ died in acute hospital. • Hospital use: 30% fewer admissions, 30% shorter stay • Costs: cost reductions per admissions **Care home initiatives** (n=3 studies, staff education on recognition of the end of life, advance care planning, optimising communication with residents and their families and documenting changes in patient preferences and condition) • Place of death: increased number of deaths in the care home compared to hospital (n=1 study) • Hospital use: reduction in hospital admissions (however in 1 RCT no significant difference in admission rates), shorter LoS, increase in non-elective admission possibly related to increased symptom recognition after introduction of multidisciplinary team. • Costs: greater cost savings and hospital reduction found in group receiving telemedicine support (n=1 study) **Palliative care support in the community** (n=18 studies, e.g. hospice at home services, including hands-on nursing care, specialist advice from multidisciplinary teams and emergency intervention) • Place of death: fewer patients died in hospital (n= 6 studies) • Hospital use: significant decrease in hospital admissions (n= 14 studies), reduction in ED attendance (in 8 of 10 studies, in 2 remaining studies no difference was found), shorter LoS (n=5) • Costs: not reported

Out-of-hours telephone line

- Place of death: not reported.
- Hospital use: significant decrease in hospital admission (n=3 studies), and in ED attendance (n=3 studies), lower readmission rates (n=1 study)
- Costs: not reported

Telemedicine/teleconsultation

- Place of death: not reported.
- Hospital use: no significant benefits found (n=2 RCTs) but reduction in hospital and emergency admissions found (n=1 retrospective study)
- Costs: not reported

Ambulance and paramedic education (additional palliative care training for ambulance and paramedical staff helping them make better decisions)

- Place of death: not reported.
- Hospital use: not reported.
- Costs: not reported

Integrated palliative care models

- Place of death: not reported.
- Hospital use: in 11 of 14 studies benefits found (with no details on which outcomes of hospital utilisation), no significant difference in unscheduled hospital admissions between intervention and control group (n=1 RCT), no effect on rehospitalisation or mortality (n= 1 RCT), more admissions found (n=1 study), fewer hospitalisations and bed days (n=1 RCT)
- Costs: not reported

Palliative care outreach in rural areas

- Place of death: 30% less likely to die in hospital (n=1 study)
- Hospital use: 30% less likely to be admitted for an emergency or attend ED, low readmissions after accessing the discharge in-reach service (n=1 study)
- Costs: not reported

Innovations supporting early hospital discharge (early PC inpatient consultation, e.g. front-of-house hospital-based discharge nurses whose role included identifying patients wanting a nonhospital death and facilitating their transfer back home)

- Place of death: not reported.
- Hospital use: shorter hospital stays (n= 1 study), significant difference in 30-day readmission in favour of intervention group (n=1 study), more likely to be discharged to a hospice (n=2 studies)
- Costs: significant cost savings linked with a shorter LoS (n=1 study)

Nurse-led inpatient initiatives (e.g. nurse-led beds for patients with less complex medical needs)

- Place of death: reduction of hospital death (n=1 study)
- Hospital use: not reported.

	• Costs: not reported
Secondary outcomes	**Characteristics of the interventions** - palliative care support in the community (including hospice at home services), provision of integrated care, out-of-hours telephone advice, care home education and telemedicine. - Nurses and hospices were central to many initiatives.

Table 1 Classification of innovations which may avoid inappropriate or non-beneficial hospital admission and/or reduce bed days for patients at end of life: definitions and sources of information

Classification of innovation	Types of innovation and examples of what is involved		Publications providing quantitative data included in this review
1 Facilitating entry into the hospice and community care system	Single point of access	Access to a range of medical, nursing and social care services for patients, carers and healthcare professionals via a single telephone number.	[27]
2 Preventing hospital admission	2a; Care home innovations	A mixed group, including training programmes for nursing home staff.	[28–37]
	2b; Palliative care support in the community, 24/7 hospice at home service	Coordinated palliative care delivered in the patient's home through regular visits by specialist medical and nursing staff, often in association with a hospice.	[38–55]
	2c; 24/7 helpline	Support for patients, carers, paramedics and non-specialist doctors and nurses.	[27, 39, 46, 48, 56]
	2d; Telehealth/ telecaring	Provision of healthcare remotely using telecommunication technology.	[36, 37, 39, 57, 58]
	2e; Ambulance staff education	Training for better communication and decision-making when attending patients at the end of life.	[59]
	2f; Integrated palliative care	Coordinated input from different healthcare professionals and caregivers.	[60–73]
	2 g; Palliative care outreach in rural areas	Palliative consultant attends the patient in their own home and coordinates care.	[56, 74]
3 Facilitate discharge	3a; Hospital or emergency department-based discharge service	Patients requesting or considered suitable for discharge into supported care (community, nursing home, hospice) are identified by a hospital-based doctor or nurse who facilitates onward management.	[56, 66, 72, 75–77]
	3b; Nurse-led palliative care inpatient capacity expansion	Offering additional nurse-led beds for less complex patients.	[78]

Source: retrieved from Taylor et al., 2020

Authors' conclusion (+ discussion)	Generally, interventions led to a reduction in emergency attendance and hospital bed days. A minority of studies found no benefits in the intervention group, while others showed an increase in hospital utilisation. Research was focused on palliative care support in the community, hospice at home services, integrated care provision, out-of-hours telephone advice, care home education and telemedicine. Nurses and hospices were central to many innovations.
Comments	/

Tedder et al., Analysis of common barriers to rural patients utilizing hospice and palliative care services: an integrated literature review, 2017[47]	
Type + number of included studies	Systematic reviews (n=3), qualitative studies (n=5), quantitative studies (n= 5), search 2010-2016
Type of participants (+ setting)	Adults hospice patients, settings not presented
Intervention vs comparator	Barriers/challenges to HC or PC, rural HC and PC, access to HC and PC and comparison of urban and rural hospices
Primary outcomes	**Geographics** • Lower socioeconomic status: poverty (more dominant in rural areas) is a risk factor for poor health outcomes; home care difficult to home design obstacles (e.g. small rooms, lack of modern conveniences) • Healthcare provider challenges: blurred boundaries between work and personal, less professional support, consultation resources and time for debriefing; more money needed to ship supplies and to drive far distances; inclement weather and poor road conditions; low staff retention and recruitment; high burden on staff. • Limited accessibility: part of zip codes not adjacent to urban area or served by any hospice; public transport not available. **Patient barriers** • Fear: sense of urgency and desire to continue curative treatments; difficult to accept reality and prognosis • Misinterpretation of services: HC and PC referrals inappropriately preconceived as negative options (giving up on a family member); well-informed patients make better decisions for care. • Rural culture: less trusting the healthcare system (due to their decreased education and increased poverty); fail to understand the physician/patient conversations relating to their terminal diagnosis, which may lead to uninformed decision making
Secondary outcomes	**Provider barriers** • Provider shortages: in rural areas physician shortages, nurse practitioners and physicians' assistance partially fill the gap but shortage of HC and PC specialty professionals. • Low provider comfort level: inadequate preparation for psychosocial care of terminally ill patients; professionals often not comfortable talking to patients and families about referral to HC and PC services; feeling of having failed. • Limited scope of practice: statutory laws limit nurses and physician assistants to admit patients into hospice (resulting in a deferred or delayed referral to care services); physician as gatekeeper; only if a patient has a terminal illness with less than 6 months to live. • Overconfidence: to manage a patient's symptoms and disease process independently blocks HC/PC utilization **Educational barriers** • Referral criteria: unfamiliarity with referral criteria, basic concepts of what HC/PC services can offer; EOL not included in prelicensure programs; referral processes often led to organisational regulations that are aimed to guide professionals, but do not individualize patient care. • Communication: feeling having failed; difficult conversations about transitional from curative to PC and comfort care services often deferred • Formal education: EOL care not thoroughly taught in most undergraduate, graduate, and medical schools; few formal education classes/continuing education easily accessible.

	Financial/policy • Reimbursement regulations: Medicare regulation; inability to receive payment to care for loved ones. • Policy barriers: Medicare policy states that patients need a 6-month until death certification from a physician and the hospice medical director / must withdraw from curative treatment (not the case with PC); patients and families often not prepared to abandon curative treatments attempts
Authors' conclusion (+ in discussion)	Potential solutions suggested by the authors: • Provider: allow NPs and physician assistants to practice at their full scope of practice • Education: incorporate HC/PC into prelicensure curriculums; enhance post licensure continuing education opportunities; accessible electronic libraries; utilization of HC pocket card care guide • Financial/policy: CMS closing the pay gap between rural and urban hospices. • Geographics: utilization of telehealth/videoconferencing • Patient: early open discussion about EOL options; confirm patient and family understanding of HC/PC services: address patient and family fears concerning misconceptions of HC/PC services; recognize influence of rural culture on EOL decisions; build community trust
Comments	/

Threapleton et al., Care toward the end of life in older population and its implementation facilitators and barriers: a scoping review, 2017[55]	
Type + number of included studies	Total n= 35 studies/reports, search 2005-2017, thematic analysis
Type of participants (+ setting)	Older populations (>60 years) approaching the end of life, UK, US
Intervention vs comparator	To identify core elements of EOL care for older populations and to present common implementation issues as resource for planning and implementing health system improvements
Primary outcomes	**Barriers per EOL component** **Macro-level (policy/contextual) factors** • Enabling policies and supportive environments: policy change barriers in nursing homes: resistance to changes, lack of collaboration, a culture of medicalization and 'striving to keep alive', systems to not reward 'just conversations' or supportive care. **Meso-level (organisational) factors** • Care pathways and models of care: poor prognostication, non-acceptance by healthcare team, insufficient resources and time for education and training, time restraints and time needed to follow care pathways. • Assessment and prognostication: trajectories are unpredictable and estimating prognosis is difficult, more contact/familiarity with patients makes prognostication harder and less accurate, generalists/inexperienced staff struggle to estimate prognosis or identify

EOL, in NH: individuals do not take responsibility for recognizing dying, health professionals often cannot recognize imminent death, which may lead to dying alone.

- Advance care planning and advance directives
  Lack of ACP knowledge (clinician and patient), delays in decision-making, doctor belief that other professionals are responsible for ACP, doctor doubts about content and practical aspects of living wills, staff lack of experience in using ACP, clinician fear of upsetting patients/families by initiating discussion, nurses who may be closer to patients and families are often excluded from planning discussions, discussions are stressful and challenging, competing work demands, fear of talking about dying in NH, conflicting patient/organisation preferences, nonelectronic notes on plans may be lost in transitions
- **Palliative care/hospice**
  Slow EOL identification, medicalized/curative model of care, PC or death seen as failure or giving up hope (e.g. mistaken belief that referral to palliative services will shorten life because life-sustaining treatments are withdrawn), limited specialised palliative services, clinicians to not have to administer the extensive treatments they prescribe to those with poor prognosis, poor clinician communication on palliative care benefits, lack of PC knowledge/skills in NH, lack of knowledge about efficacy and purpose of PC among nurses/clinicians
- Integrated and multidisciplinary services
  Lack of multidisciplinary collaboration with NH, lack of coordination or care registers leads to inappropriate hospital admissions at EOL and loss of medication or care preference details.
- Resources
  Lack of physical space in hospitals to have family visits/discussions, insufficient physical space in hospitals to die privately, insufficient time and resources to care for patients in NH, care home improvements are limited by time and available staff, staff have insufficient time to deliver effective EOL care in intensive care units, taking time with a dying patient is not prioritized or supported in busy settings, shortage of hospice nurses and nurses experience fatigue in dealing with dying patients

Micro-level (individual) factors

- Effective communication
  Inadequate communication is the most significant barrier to good EOL care, death is taboo and difficult to discuss, clinicians lack skills and confidence to tackle EOL discussions.
- Staff experience and training
  Time restraints, limited access to resources and limited computer skills, community clinicians may be unsure of procedures and available services, staff lack of education and experience in EOL discussions and care, NH staff resistance to change, nurses have insufficient knowledge and training about clinical decisions at EOL including clinician reluctance to prescribe high dose analgesia, lack of understanding around care goals, insufficient medication knowledge.
- Emotional and spiritual support
  Patients worry about pain and control of physical and emotional symptoms, patients may experience depression, anxiety, spiritual distress, family breakdown, financial strain and social stigma, clinicians are not reimbursed for ‘talking’ with patients and listening to their thoughts and wishes.
- Personalized care (patient and family involvement in decision-making)

	Unrealistic family expectations, conflicting family opinions, patients and caregivers lack knowledge about available services and how to access them, lack of family participation in care planning, unrealistic expectations of death, family/patient denial of death, death is taboo and difficult to openly discuss, denial of death and difficulty in making decisions, families may pressurize patients into accepting more aggressive forms of care
Secondary outcomes	List of facilitators per EOL care component: see table 2 **Facilitators specific to hospice care:** • Rapid community response team and rapid discharge planning for death at home • Discussion soon after terminal diagnosis helps with acceptance to hospice care. • Home-based PC is facilitated by creating care goals, communication and skill enhancement for primary care team and patients/caregivers. • Cultural shift away from viewing death as failure • Mandatory, ongoing training and education on EOL care (especially for doctors) • Patients/families understand disease pathology, accept prognosis, and participate in decision-making. • Physicians take an active role in recommending hospice care and facilitating service transfer. • Specialised palliative care teams. • Hospices are identified as rich sources of experience that can mobilize and train generalists in the community and care homes. • Hospices may act as organisational hubs within the community and recruit volunteers
Authors' conclusion (+ in discussion)	Principal issues concern inadequate policy and guidelines for supporting key aspects of EOL care, or systems that lack important elements, such as integrated services or ACP. In terms of individual staff, key problems include experience and training, and the cure culture among clinicians and care professionals. Poor communication was often noted as one of the most significant barriers to quality care at EOL.
Comments	Rapid scoping literature review NH: nursing homes

Tobin et al., Hospice care access inequalities: a systematic review and narrative synthesis, 2022[46]	
Type + number of included studies	N= 130 included studies, Search up to 2019
Type of participants (+ setting)	Adult patients in UK, Australia, New Zealand, and Canada, receiving inpatient, day, outpatient, and community hospice care
Intervention vs comparator	Demographic characteristics of hospice care patients: diagnosis, age, gender, marital status, ethnicity, geography, and socioeconomic status
Primary outcomes	**Inequalities in access in relation to diagnosis** • Reduced access for non-malignant disease (including heart failure, non-cancer respiratory disease, renal and liver failure, mental health, learning disability, dementia, and neurodegenerative disease (except for motor neuron disease)) but hospice access is increasing in UK, Canada, and Australia

	• Greater hospice referrals and/or deaths for patients with cancer, but lower hospice provision for those with haematological malignancies **Inequalities in access in relation to age** • The oldest old (>85y) are under-represented in hospice services. Centenarians seldom die in UK hospices, however recently more over 85-year-olds are accessing hospice care in UK. **Inequalities in access in relation to gender** • Inconsistent findings: women more likely to access HC than men however other studies suggested the reverse of reported no differences. **Inequalities in access in relation to marital status** • Inconsistent findings: married individuals were more likely to access hospice services, other studies found marital status to be unrelated to hospice access. **Inequalities in access in relation to geography** • Access is greater for those living in urban areas, with closer proximity to a hospice and associated services. • Availability of services varies considerably between regions and countries, which may act as barrier to GP referral. **Inequalities in access in relation to socioeconomic status** • Lower hospice access for people living in areas of lower socioeconomic status. • However conflicting results: some studies report no association or greater access among those from lower SES areas. **Other factors** • Negative public and professional attitudes towards hospice services • Challenges of difficult conversations surrounding the term 'hospice'. • Extent or lack of a patient' social support networks
Secondary outcomes	**Inequalities in access in relation to ethnicity and religion** • People from ethnic minority groups are less likely to receive hospice care
Authors' conclusion (+ discussion)	Need for a shift from a historical cancer-appropriate 'on-size-fits-all' framework to new model of hospice care to prioritise whichever patients need it the most and to better identify those patients with non-cancer illnesses who would benefit from hospice care. Innovative collaborative services based around patient, family and wider community are needed to ensure optimal care for all. Greater focus is needed on addressing the needs of minority groups. Public awareness of what hospice care provides and for whom will increase access to hospice care.
Comments	Hospice care was broadly defined to include inpatient units and beds, day therapy, outpatients, hospice at home, community hospice teams, Macmillan and Marie Curie nurses, hospice chaplains and hospice social workers.

Vernon et al., Measuring effectiveness in community-based palliative care programs: a systematic review, 2022[9]	
Type + number of included studies	N= 61 studies (n= 19 qualitative results, n=50 studies with quantitative results), reporting on 52 community-based PC programs
Type of participants (+ setting)	?
Intervention vs comparator	Comprehensive community-based PC programs Studies that focused only on a single component of community-based PC program were excluded from this review → reported in Hughes, 2023[8]
Primary outcomes	**Characteristics of community-based PC programs across the included studies** • All were described as interdisciplinary. • Composition of the team: nurses most common member of the team, followed by doctors and social workers, volunteers in 19% of the programs, spiritual care support workers and counsellors in 15% of the programs. Case coordinators, pharmacists and physical therapists mentioned as team member in more than one CBPC program. • Programs: various forms of symptom management and care coordination, patient and caregiver education explicitly note in 30% of the programs, telephonic support services (most often provided by nurses) in 26% of programs (15% 24H a day), respite services in 9% of programs, other services mentioned in more than one program included advanced care planning support and domiciliary services **Utilization** • In majority of studies: positive findings • Conflicting evidence: lower hospital utilisation rates in 10 studies, in 3 studies no positive results • Length of stay: all 6 studies reported lower LOS. • ER visits: in 4/6 studies reduced rates. • Hospice utilization rates: higher rates suggesting a successful outcome for CBPC. **Costs** • Australia (2 studies): lower hospital costs for all sickness groups, except motor neuron disease patients (no difference compared to non-program patients) • Canada (3 studies): lower overall costs in 2 studies, in 1 study no difference • UK (3 studies): lower overall costs in 2 studies, in 1 study lower costs for patients in last year of life but no difference in total costs to the healthcare system • US: majority of studies reported lower healthcare costs **Location of death** • In 12 studies: favourable outcomes related to location of death and CBPC program enrolment (more at-home death and less hospital deaths)
Secondary outcomes	**Satisfaction (reported in qualitative studies): overall satisfaction by the CBPC experience** • Flexibility and preference for place of death: drivers for patient and family satisfaction • Strong team building: driver of provider satisfaction **Support for health care professionals and volunteers (reported in qualitative studies)**

	• More communication on social and emotional issues would be beneficial. • Education and training related to using technology were needed. **Patient-centred needs (reported in qualitative studies)** • Importance of catering to the personalised needs of patents with CBPC • Patients valued being treated with dignity and respect. • Patients' desire to maintain a sense of independence and normalcy can be barrier to participation. **Quality of life (reported in quantitative studies)** • Conflicting results: improvement vs no difference **Advance care planning (reported in quantitative studies)** • Conflicting results: positive relationship between CBPC enrolment and ACP vs no positive impact
Authors' conclusion (+ discussion)	This systematic review suggests that some, but not all, CBPC programs have achieved positive results. Most notably, the review strongly indicates that CBPC programs impact the location of death.
Comments	Unclear reporting of results which hampered analysis. Analysis of the included studies needed, but not possible due to time restrictions in project

Wong et al., Gender disparities in end-of-life care: a scoping review, 2023[43]	
Type + number of included studies	SR (1), quantitative studies (6), qualitative studies (6), letter to the editor (1), critical essay (1), all published between 2011 and 2020
Type of participants (+ setting)	Inpatients in Sweden, UK, Germany; hospice patients in UK, US, Portugal; cancer centres in US; older women in New Zealand
Intervention vs comparator	Access to end-of-life care (including related aspects, such as preferences, social and care context, coping strategies) versus delayed or no access, due to (potential) gender disparities
Primary outcomes*	**Care context** Women: • Received medical care primarily from generalists (family physicians) versus men received medical care primarily from specialists: women looked for continuity of long-term relationships with GP as source of support versus men's expectations about 'faint hopes' of cure. • Shorter hospitalizations, more likely to die in nursing homes than at home: greater willingness to accept formal care as not to be a burden on family members + more limited possibilities for informal care after outliving their spouses. **Care preferences** Women: • More DNR order + fewer received care in ICU

	• Less likely to ask for or prefer informal care from family members (fearing to burden others) + more accepting of dying outside the home (to alleviate the burden) • Preference for palliative care rather than curable treatments • Less likely to benefit from early palliative care. • In some settings + diagnoses: social castigation and ostracized from family, no social network to provide EOL care. Men: • Higher expectations of receiving care at home from wives, and of retaining autonomy in making such decisions: gender bias in being more reluctant to take advice from female HC professionals. **Caregiving** Female caregivers: • More mental and physical strain, lower self-esteem, higher levels of fatigue: greater expectations and responsibilities placed on women as caregivers and increased burden on their own health (universal belief that women are natural informal caregivers of society) • Heightened feelings of guilt or failure when unable to do so (due to diagnosis with multiple medical conditions) • Less likely to qualify for government financial support benefits (generally linked to employment) + received less money (related to lower income) • **Men**: underutilized formal support HC professionals: • Physical care delegated to women and decision making to male caregivers. • More support to male caregivers • Women were assumed to inherently be more compassionate, sensitive to others, and willing to put others before themselves, for men not the same standard. • Unaware of their unequal expectation of males and females and rendered women's work invisible and undervalued. **Coping strategies** Women: • more able to express needs and ask for help. • better at communicating about pain, using wider vocabulary, and including cognitive and psychological terms. • symptom control more a shared goal. • activated extended networks for support. • valued and used physical appearance more at EOL to retain control and agency: cultures and locations that place stronger value on appearance. Men: • tried to be strong and independent. • rely on their partners
Secondary outcomes	**Living situation** Women:

	• less likely married, more likely to be widowed, more likely to be living alone at EOL + older at EOL (+ higher prevalence of chronic diseases and chronic pain conditions) • more often found living in poverty: gender inequities earlier in life (unequal pay and working conditions) **Symptom experience** Women: • Higher symptom burden: Reported more pain, fatigue, and nausea (however no difference in medical charts or documentation) • Undertreatment for pain not heard by HC professionals (societal belief pain is likely exaggerated and related to anxiety and emotional distress and natural process that needn't be treated) • Experienced less improvement in QOL when palliative care was initiated, due to difference in worries (unmet responsibilities for domestic and caring duties versus financial and legal duties in men) Men: • More depression at EOL (related to expectation that men should be independent): dose dependent relationship between frequency of depression and level of dependency
Authors' conclusion	The push for more end-of-life care in the community may unfairly burden women who shoulder most caring duties but receive less care support. All the 6 domains (outcomes) were clearly linked to deeply ingrained social constructs of sex/gender with each creating inequitable expectations at end of life. Women: limited financial resources compared to men, greater life expectancy with harm of widowhood, greater burden of symptoms; lifelong toll of continuing to dutifully care, importance of physical appearance. Men: vulnerability is seen as weakness; this can discourage seeking end of life support or communicating feelings and symptoms to HC professionals. Men rely more on themselves rather than an extended network for support.
Comments	Most studies have been conducted in past 10 years, but small sample sizes and limited internal and external validity

Woodman et al., The preferences and perspectives of family caregivers towards place of care for their relatives at the end-of-life. A systematic review and thematic synthesis of the qualitative evidence, 2016[59]	
Type + number of included studies	Qualitative studies (n=18), search up to 2014
Type of participants (+ setting)	Bereaved or current adult family caregivers of adult patients receiving end-of-life care, Canada, Australia, UK, Sweden, Hong Kong, Denmark, Singapore, USA
Intervention (vs comparator)	Family caregivers' preferences, attitudes, and perspectives on place of end-of-life care
Primary outcomes	**Preferences and perspectives of family caregivers regarding place of care** • Place of care ○ Home: preferred place of care ▪ Facilitating home care was recognised as achievement by family caregivers.

        - However: emotional cost of caregiving + deteriorating relationships and family conflict → emotional and physical burden led to admission into formal care settings
        - Admission does not change preference relating to place of care, but they simply felt unable to cope at home any longer
    - Hospice: preference to be cared for (if admission is needed)
        - Admission: allowed them to connect emotionally with their relatives without the distraction of providing physical care
        - Hospice services were considered a lifeline inspiring the confidence to continue caring at home.
        - Perceptions surrounding hospice improved if family caregivers used their services: change from viewing hospices as place of suffering to a compassionate place of care.
    - Location preferences could change over time (from home to hospital) if distressing symptoms made home care difficult.
    - Hospital: unsuitable palliative care environment, due to its impersonal nature (except in small community hospitals due to quality and personal nature of care provided)
    - Respite care: differing opinions (preference not to leave their relatives vs describing it as valuable and enabled care at home to be facilitated for longer)
    - Lack of knowledge about palliative care services provision: related to accessing support services, existence of palliative home support, and hospice involvement in palliative care.

- Decision-making regarding place of care
    - Shared decision-making was preference + improving communication eased caregiving burdens.
    - Factors determining preferences for home care: positive perspectives of home care, caregiving described as meaningful and a privilege with the home being where optimum care took place + facing expectations from their relatives.
    - Little consideration of needs of family caregivers by HCPs: feeling internalised obligations to facilitate care at home (moral duty or promise), feeling obligated to provide care left caregivers with little choice but for home to be the place of care, had no choice but to care at home, own preferences were unimportant often ignoring them to facilitate the patient's preferences.
    - Preferences surrounding other place of care varied with local care provision: local palliative care services could facilitate or hinder caregiving.
- Facilitators and barriers to caregiving
    - Facilitators: a resilient personality or strength within yourself, good family relationships, knowing that their relative was appreciative of the care received, feelings of reciprocity
    - Need for support (though not always attained or expected): when making decision to care, discussing the future and when caring at home.
        - Informal support networks: emotional support and practical help
        - Formal support from health services and HCPs: great importance, providing security to enable care to continue at home, provision of information (how to physically care and supportive care services available), practical relationships with formal support networks promoted distribution of responsibility, sense that HCPs were involved was considered beneficial.

	▪ Support (both formal and informal) had a substantial impact on family caregivers' ability to cope with caregiving role. ○ Barriers: difficulties reported when they were unprepared for, or could no longer cope with, home care + when no choice or little or no discussion about their own needs and preferences, caregiving was unduly burdensome + failures in informal and formal support networks (e.g., increased caregiving burden when close friends are uncomfortable with realities of dying, lack of support from HCPs) + over-abundance of support gave impersonal aspect **Impact of caregiving on family caregivers** • Impact of facilitating home care ○ Positive impact: allowing them to demonstrate love for their relative, experiencing the illness trajectory was beneficial, allowing families to feel greater sense of 'togetherness'. ○ Negative impact: little escape from caregiving role, meaning of 'home' changed (becoming an impersonal and medicalised environment), feeling ignored and alone, sense of isolation. • Following through the promise for home care (home death) ○ Caring at home until death: great significance for family caregivers ○ Managing or failing to do so: greatly affected family caregivers before and after bereavement. ○ Facilitating home death: feelings of accomplishment, positively impacted bereavement experience ○ Failure of home death: substantial negative impact on family caregivers, negatively impact bereavement experience (ideas of failure and guilt)
Secondary outcomes	/
Authors' conclusion (+ in discussion)	• Home is considered as the preferred place of care but also reported sense of obligation. Informal and formal support has a largely positive effect on home care experience. Based on the reported positive and negative perspectives and experiences of caregiving at home, this may not be appropriate for all families. • Patients' and family caregivers' preferences for place of care may change over time, but often result of family caregiver being unable to cope in caregiving role. Place of care could also differ from place of death, with hospice admission at EOL as positive outcome. • Unmet needs of family caregivers (communication, psychosocial issues, sense of isolation, feeling unprepared and unsupported) often leading to hospital admission. Caregivers should be made aware of the commitment and burdens of caregiving before agreeing to provide EOL care and support services should be available (with needs assessment tools and ACP documents).
Comments	Some subjective bias by authors (interpretation of the findings of the included studies) Most studies on cancer patients

Wu et al., Palliative care service utilization and advance care planning for adult glioblastoma patients: a systematic review, 2021[50]	
Type + number of included studies	Retrospective cohort studies (n=10), cross-sectional studies (n=3), prospective cohort studies (n=2), case-control study (n=1), Search up to 2020
Type of participants (+ setting)	Adults with GBM diagnosis, USA, Canada, Austria, Germany, Italy, Australia
Intervention (vs comparator)	Prevalence of advance care planning (ACP), EOL services utilization (including PC services) and experiences among adults with GBM
Primary outcomes	**Healthcare utilization at the EOL** • PC utilization: PC referrals ranged between 39 and 40% (+ at least 3 days to 33 days prior to death), PC consult utilization between 34-36%, median time from diagnosis to PC consult 111 days. • Hospice: referral rates ranged between 66% and 76%, utilization ranged from 38% to 86%, timing of referral and enrolment varied between studies (38% in last 2 weeks before death vs 23% of home hospice patients enrolled within 7 days if death vs.) • Hospitalizations at or near EOL (in the last month of life): ranged from 37% to 42%, average LOS of 8.75 days, 34% had ICU admission, 20-56% of patients spent over 25% of their overall survival time hospitalized. **Patient-reported experiences** • Other symptoms (= symptoms other than pain) of minor importance • Familial anxiety and patients' own illness-related anxieties of high importance • Problems experienced in the recent past (Palliative Outcome Scale): health-related impairments (33%), worries about the future (11%), loss of everyday skills (10%) • Life priorities (Life Priorities Survey): 'live as long as possible, no matter what' most frequently ranked in patient's top three goals, '(being) mentally aware' and '(being) independent' were 'somewhat to extremely important'. **Caregivers' experiences** • Job restrictions that impaired their caregiving abilities (50%), felt incompletely prepared for their tasks (29%), financial difficulties as significant barrier (29%) • Financial difficulties were associated with caregiver burnout (60%) and reduced quality of life (impaired QoL comparable to that in GBM patients themselves) • Insufficient time for self and stress between caring and other responsibilities also common challenges • Did not feel overly burdened by patient's illness-related symptoms (e.g., embarrassment over patient behaviour) and did not endorse a feeling of being 'unable to care for relatives any longer' or wishing to leave the 'care of relative to someone else'
Secondary outcomes	**ACP conversations and documentation** • Prevalence ranged from 4% to 55%, 11% of patients ACP documented before their diagnosis, 29% within 6 months after diagnosis, 54% at their last follow-up and among decedents 55% prior to death. • ACP or goals of care conversations: most frequently discusses EOL planning (including hospice and PC), prognosis, and prognostic understanding. • None reported healthcare proxies, family involvement, or information preferences.

	Location of death • In 3 studies: death was most common in-home setting (39-64%), but in three other studies death in other healthcare facilities (including hospitals and skilled nursing facilities) was more common (up to 78%) • Preference for location: 45% of patients who desired to die at home, 68% died at home, 27% in hospital, 5% in hospice. • Hospice, whether inpatient or at home, was listed as location of death for 12% to 64% of patients
Authors' conclusion	Our findings continue to suggest that the adult GBM patient population would benefit from more and better ACP. Existing programs and quality measures used in other cancer populations could be translated into GBM management. Little data were available about the decision-making underlying the timing of hospice referrals and whether these referrals were based on qualitative scales of functional status or disease and treatment course. Overall, there is much room for improvement in palliative and hospice services utilization by patients with aggressive and incurable diseases, such as GBM.
Comments	/

5 APPENDIX V - DETAILED DESCRIPTION OF THE PALLIATIVE CARE OFFER IN 4 BORDER COUNTRIES OF BELGIUM

5.1 The Netherlands

5.1.1 Whole context of palliative care services

The hospice and palliative care movement in the Netherlands started 35 years ago as a non-medical volunteer movement. The national legislation to regulate PC provision takes the form of a general law on health care with reference to PC and includes a legislation on end of life issues but does not include a law specific to PC.[62] A legislation that went into effect in 2002 permits both assisted suicide and euthanasia under certain conditions.[63] In the Netherlands, PC is a competence of the Ministry of Health, Welfare and Sport.[62]

In 2014, the first National Palliative Care Programme (NPPZ I) was launched and ran until 2020. At that moment, the Dutch government had planned to take palliative care to a higher level. The aim was for people in their last phase of life and their loved ones to receive the care and support that matches their wishes and needs, where and when they want it. The plan defines objectives like increasing end-of-life awareness; removing barriers in funding and organisation of palliative care; standardizing quality requirements for palliative care on all dimensions; and sensitizing and supporting professionals to involve patients and relatives in the palliative care process. In the frame of the NPPZ I, several decisions were taken like[64]:

- The development of a *Kwaliteitskader Palliatieve Zorg* (Quality Framework for Palliative Care) to promote and ensure quality of palliative care.[65] The document was published in 2017. The aim of the quality framework is to improve palliative care provision from the experience of patients and their loved ones by describing what patients, healthcare professionals and healthcare insurers mean by good palliative care. It addresses all aspects of it.
- The creation, in April 2018, of the *Palliatieve Zorg Nederland* (PZNL), an organisation that focuses on promoting and improving palliative care. It has been commissioned by the Ministry of Health, Welfare and Sport to optimize cooperation in palliative care.[66] This is operationalised by setting up regional coordinating networks (see next bullet), by organizing education and training for all stakeholders in palliative care, by creating and providing practice guidelines and standards, by initiating quality improvement initiatives (campaigns), and by facilitating information exchange.
- The creation of palliative care networks, formal and long-term partnership of independent organisations involved in palliative care in a specific region. There are 65 regional palliative care networks in the Netherlands. The networks were initiated to promote cohesion in interdisciplinary care, with the aim of contributing to the highest possible quality of life and death, based on the values, wishes and needs of the patients and their loved ones. The Dutch government stimulated palliative care networks through an incentive scheme. PZNL provides support to the Palliative Care Networks.
- The financing by the Dutch government of a research programme aiming to improve the quality of the PC in the Netherlands called “Palliantie. Meer dan zorg.” which took place from 2014 to 2020.[67]

Since 2022, the second National Palliative Care Programme (NPPZ II) was launched in the Netherlands. This second plan mainly aims to monitor the impact of the ongoing programmes on patients and families, on the collaborative process and on the organisational structure. The NPPZ II notably represents the implementation of the Netherlands Palliative Care Quality Framework, with palliative care becoming part of the regular care process. This second plan also includes a research programme called “Palliantie II” which focuses on a good quality of life for people dealing with a life-threatening condition or vulnerability through care and support in physical, psychological, social and spiritual areas that match their wishes and needs.[68] NPPZ II plan lasts till 2027 and is coordinated by Stichting PZNL (the PZNL Foundation). The PZNL Foundation, created in 2022, is mainly made of a network of organisations with a wide variety of partners who play a role in palliative care and its support.[66] So the Netherlands stands

out for the development of strategic plans which, as well as being implemented, are also monitored. The main current focus is the collaboration and coordination, and inovations in care quality.

The Netherlands has three umbrella organisations that coordinate, supervise and lobby for their specific palliative care housing initiatives. Each has its own quality framework or compass. Affiliation with an umbrella organisation is not mandatory, but palliative care housing initiatives must be member of a palliative care network.[69] Those three organisations are *Vrijwillige Palliatieve Terminale Zorg Nederland* (VPTZ), *Associatie voor HospiceZorg Nederlands* (AHZN) and ACTiZ, a trade association for organisations in elderly care and care for people with a chronic condition. Also, organisations related to cancer are all very engaged to promote high quality and awareness in palliative care : the *Koningin Wilhelmina Fonds* (KWF)[70], the *Nederlandse Federatie van Kankerpatiënten Organisaties* (NFK)[71] and the *Integraal Kankercentrum Nederland* (IKNL)[72].

In the Netherlands, non-specialised medical PC is delivered by general practitioners and specialists who have not undergone specific training in palliative care, but who have received some knowledge of palliative care as part of their basic medical training. Home care and hospital nurses whose have also benefited from general courses in palliative care during their basic studies also delivered non-specialised PC.[62] Compared to other countries studied by EAPC experts, the Netherlands stands out for its better ability to identify patients eligible for palliative care through the first line of care.[62]

Different types of specialised palliative care are available in the Netherlands. At home; the beneficiary can receive care of volunteers-led PC team or nurses specialised in PC, in addition to generalist PC provided by the patients' general practitioner, the home care nurse, and informal caregivers. In Long Term Care Facilities (LTCF), the vast majority of staff is trained in palliative care. In hospital, patients may either be admitted to a palliative care unit (PCU) or be followed by an intra-hospital mobile team when staying in any other care unit. Inpatient hospital care is relatively rare in the Netherlands and focuses on patients with very complex needs and/or requiring highly technical care at the last phase of life. However, it is supplemented by three other types of inpatient services outside hospitals: (i) palliative care units within LTCFs, (ii) hospices run by volunteers (*Bijna Thuis Huizen - BTH*) and hospices run by professionals (*High Care Hospices - HCH*). These home and residential care services are complemented by day centres and transmural palliative care consultations during which HCP provide advice but do not deliver direct care to patients. Since 2012 there is one clinical day treatment center and 5 non-clinical day treatment centres (only supportive care) for outpatient care or day admission. These are organisations that are responsible for the reception, accommodation and follow-up of palliative patients during the daytime. So it is not possible to stay there 24/7.

5.1.2 Description of hospice inpatient services

The first hospice in the Netherlands opened its doors in 1989. It was a small-scale initiative in Nieuwkoop (between Leiden and Utrecht) led by informal (non-professional) caregivers. Since then, the number of hospice beds has increased every year.[73, 74] At the end of 2023, 225 inpatient hospices met in total 1206 beds, were located in the Netherlands.[75] This growth is not surprising; the demand for hospice care in the Netherlands is increasing.[73, 74, 76] New hospices are created every year, often from a citizens' initiative. Hospices are never a stand-alone structure in the Netherlands.

Hospices are a link of the chain of palliative care. Half of the patients admitted to hospice inpatient services come from hospital. Hospices must connect with (embed in) a network of palliative care. This implies that other palliative care services, besides the hospice care, are always reachable. Hospices are in fact in between the hospital palliative care and the home palliative care.

Over the last decades three types of hospice inpatient initiatives have been developed: *Bijna Thuis Huizen*, High Care Hospices and Palliative Units in nursing homes.

- **BIJNA THUIS HUIZEN** (n=120): *Bijna Thuis Huizen* (BTH) are originally citizens' initiatives and is regarded in the literature as a 'volunteer driven hospice'. It is a house with about 4 to 6 rooms and guest rooms for family and other loved ones.[77] Most people go to a BTH to die. But it is also possible to stay there for a while with the aim to give to informal caregivers some rest (respite care) or to ask the hospice doctor

(dedicated GP or specialist) to treat symptoms. After that, it is still possible to die at home if wished.[78] The care in BTH is provided by trained volunteers and is professionally supported by one or more home care organisations, external HCP and independent contractors (e.g. cleaning servies, catering). Medical management is the responsibility of a general practitioner, generally the individual patient's own general practitioner.[79] A senior palliative care physician is regularly involved as an external consultant.The patient can keep any other care professionals like at home.[80] The care is completely moved from home to BTH.[80] Like home situations, most of the day and evening care is provided by informal care givers, i.e., family caregivers and trained volunteers. The volunteers add to the family care from within their role of 'being there' for the patient and relatives. Night care is often assured by the presence of a nurse.[81] Often, home care nurses are involved to support the informal caregivers with more specific nursing-related tasks, such as washing, medication therapy, wound care, …[82] Forty-five percent of the BTH also provide volunteer's support to people in the terminal phase at home.[76] In some BTH, volunteers who work at home and in the hospice are distinguished, while elsewhere volunteers rotate between the two systems.[79]

- **HIGH CARE HOSPICES** (n=41): High Care Hospices (HCH) are also often originally citizens' initiatives that arose in collaboration with regular care professionals and have grown into small-scale independent care organisations specialised in palliative terminal care. A HCH is a building with in most cases 6 to 10 rooms plus guest rooms.[76] It offers a great deal of expertise and delivers complex palliative terminal care. It employs permanent staff such as coordinators, nurses, volunteers and, in some institutions, spiritual informal caregivers.[83] A HCH has its own nursing staff or works together with a permanent specialised nursing and care team (e.g. assistant nurses) of a home care professionals organisation.They also collaborate with other care professionals such as general practitioners, physiotherapists and medical specialists but in most of the case, medical care is provided by either the own general practitioner or a dedicated hospice doctor (GP specialised in palliative care). HCH cooperate with trained volunteers' organisations. The role of volunteers in HCH is more to support the professionals which are in the lead and engage the volunteers to help with care tasks and to be present with the patients. The patients' family or other close relatives can also help. Most HCH do not have their own WTZa (Wet Toetreding Zorginstellingen) recognition[84] but are subcontractors at (collaborate with) a home care organisation or a nursing home. Most of the HCH meet the quality requirements of the PREZO Hospice Care quality mark (see further), which is based on the Quality Framework for Palliative Care in the Netherlands.
- **PALLIATIVE UNITS at nursing homes** (n=62): Palliative Units (PU) have been initiated by nursing homes and come in a variety of forms: from a few rooms in a care unit to a separate accessible unit with its own living environment. Care is usually provided by a specific team. In addition, paramedics from the nursing home can be deployed. Volunteers are involved in limited numbers. The medical care at a PU is the responsibility of the geriatric medicine specialist physician or a palliative care specialist. A PU is referred to in the literature as regarded as a 'professional driven hospice'. They work according to the Nursing Home Care Quality Framework and the Quality Framework for Palliative Care.

5.1.3 *Financing of hospices*

Financing of specialised palliative care in *Bijna-Thuis-Huizen* and High Care Hospices is often a patchwork. There is no integral funding and funding is often historically determined. In practice, this means that hospices are funded from many sources. Almost all BTH and HCH services are partly dependent on donations or sponsorship. A 2009 study by *Palliactief* (the multidisciplinary professional association for professionals working in palliative care) shows that 94% of the respondents need additional resources in the form of donations or sponsorship.[85] HCH and BTH have the option of qualifying for a statement of the Tax and Customs Administration as a Public Benefit Institution (*Algemeen Nut Beogende Instelling*). As a result, donations are deductible for income tax.

Since the '90s, the Ministry of health provided the mainly volunteer-driven hospices with some basic financial support. This was of great help, but it could not cover all expenses. In 2007, subsidy regulations were established,

providing all the hospices in the Netherlands with a steady flow of basic finances for housing, coordination and training of volunteers, based on the number of patients supported in a certain period.[86] Currently, the financing of housing is not included any more in the subsidies (stop since 2021).[87] Coordination and training of volunteers in BTH is funded from the national PTZ funds, a subsidy scheme for Palliative Terminal Care from the Ministry of Health, Welfare and Sport.[79]

When receiving care in a palliative hospice, patients typically do not have to pay additional out-of-pocket costs for the basic healthcare services provided (e.g., the care by a community nursing service), as they are covered by the compulsory healthcare insurance. These basic healthcare services may include medical and nursing care, pain and symptom management, psychological support, and assistance with daily activities. Chronic care can also fall under the *WLZ* (*Wet Langdurige Zorg* – Long-term care Act).[88] However, in BTH a personal contribution is customary for food and accommodation. In a BHT, cost for the stay is only paid by supplementary insurance. This also applies to many PU and HCH but only until 2025 because, from 2025, stays in a PU and HCH will be covered by the ZVW (*zorgverzekeringwet* – law on compulsory healthcare insurance) in the frame of covered *eerstelijnsverblijf* (stay in the community). Finally, it is important to note that there may be certain conditions or additional services that fall always outside the coverage and might require additional payment. Examples of such are certain therapies, specific types of equipment or medication not covered by the standard insurance package. Those who do not take out supplementary insurance pay additional out of pocket costs.[89]

In addition, there is sometimes funding for social services and aids from the Social Support Act (*WMO – Wet Maatschappelijke Ondersteuning*). But this funding is incidental. Municipalities can decide for themselves whether they want to contribute to the WMO. This happens in approximately 50% of hospices.

5.1.4 Access to hospice inpatient services and target population

Until 2019, a certificate of terminal illness was required to access hospice inpatient services, but this is no longer the case. At that previous time, a medical doctor (GP or specialised physician) investigated the person and issued a so-called 'terminality statement' (*terminaliteitsverklaring*) also called a *PTZ* statement (*Palliatieve Terminale Zorg indicatie*)[a]. This terminality statement has caused a lot of dissatisfaction among patients and healthcare professionals because it was patient-unfriendly and caused unnecessary administration tasks. Moreover, it was never possible to say with certainty whether life expectancy is actually shorter than three months. So since November 2019, it is no longer necessary to use a terminality statement in most situations. Various parties from the healthcare sector and the Ministry of Health, Welfare and Sport have agreed on this.[90]

Now, the criteria for admission to a palliative hospice in the Netherlands vary slightly depending on the hospice and the region. The decision for admission to a palliative hospice in the Netherlands is typically made through a collaborative process involving individuals and healthcare professionals. The ultimate decision may vary depending on the circumstances and the policies of the hospice. But in general, the following criteria remain the same:

- **Illness stage**: Palliative hospices generally admit individuals who have a terminal or life-limiting illness. These may include conditions such as advanced cancer, end-stage organ failure, advanced neurological disorders, or other progressive illnesses where curative treatment is no longer the primary focus.
- **Prognosis**: The individual's prognosis remains an important factor in determining admission to a palliative hospice. Typically, individuals with a limited life expectancy, often estimated to a few months or less, are considered for hospice care. However, specific timeframes may vary depending on the hospice and individual circumstances. It is still possible that people with a life expectancy of 3 months or more could

[a] More information: https://sterinzorg.nl/laatste-levensfase/palliatieve-en-terminale-zorg/terminale-zorg/wat-is-een-terminaliteitsverklaring/

not be eligible for admission in a hospice.[76] However, if the patient lives longer than 3 months, the patient can stay longer. If someone recovers -which happens regulary- they must be moved to a nursing home or returns home.

- **Palliative care needs**: Hospices are designed to provide specialised care for individuals with complex palliative care needs. The individual may require support in managing pain and symptoms, emotional and psychological support, spiritual care, and assistance with activities of daily living.
- **Empowerment**: The decision to enter a palliative hospice is usually made by the patients or their family in collaboration with healthcare professionals. It is important that the individual has an informed understanding of their condition, prognosis, and the goals and nature of hospice care. Admission to a palliative hospice requires the individual's or their legal representative's consent. The individual or their representative should be actively involved in the decision-making process and agree to receive care in the hospice setting.

5.1.5 Profile of patients admitted in hospice inpatient services

At hospice admission, no significant differences in patient characteristics were found between the three hospice types. In other words, patients' profiles are the same when admitted to any hospice. Patients and referrers do not seem to choose a particular type of hospice based on specific care needs.[69]

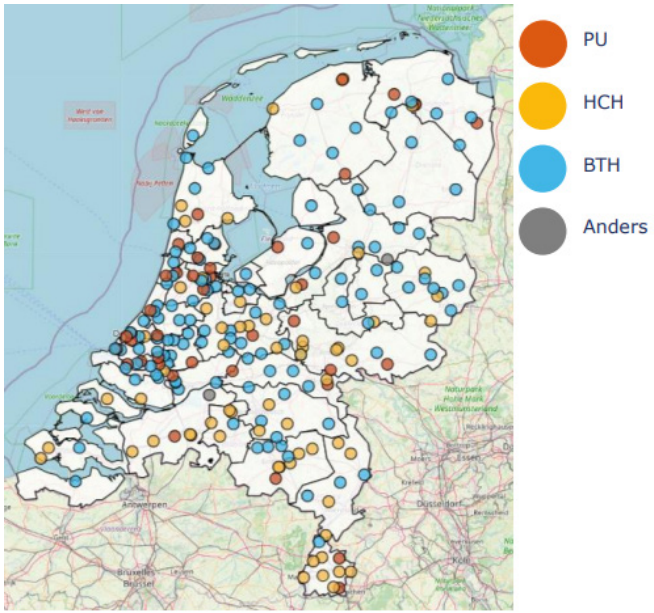
According to 2016 data, about 84% of patients applying for hospice inpatient services had cancer compared to 37% of deaths nationally. Fifty-two percent of applicants were hospitalized before their admission to a hospice. Most frequent reasons for application were the wish to die in an hospice inpatient service (70.5%), needing intensive care or support (52.2%), relieving informal caregivers (41.4%) and needing pain/symptom control (39.9%).[91] The most frequent reason for not (timely) being admitted to inpatient hospice services is the death of the patient, suggesting that this group might have benefitted from considering applying to an hospice inpatient service earlier on.[91] More recently, the last registration report of VPTZ (2023) indicates that a common reason for admission to a hospice is relieving overloaded informal caregivers (43%).[76]

Recent results of the HOPEVOL research project[92] highlighted that the typical palliative patients are both men and women around the age of 75. They have almost all a Dutch origin and are often married or widowed. Patients primarily have cancer diagnoses, are supported by informal caregivers, have a predicted life expectancy of between 1 and 3 months, and access hospices for the purpose of end-of-life care. Patients with non-malignant disease and non-Dutch cultural backgrounds are less likely to access hospice care. The median length of stay is 14 days. Half of all people stay in hospice between 6 and 36 days. All admitted patients have physical complaints, 50% have psychological complaints, 33% have social care needs, 25% have questions on existential topics. In 3 to 6% there are problems in all four dimensions, in 25% in three dimensions.

In the first 72 hours after admission, the status of half of patients is of low complexity, 25% of medium complexity, 7% of high complexity. This shifts to a more complex status during the stay with 13% high complex in the last 72 hours. Complexity of care is determined by a combination of dimensions, the social system around the care recipient and the context of the hospice. The tool PALCOM was used to assess the level of complexity.[92] Stability, appropriateness of care (appropriate care are care that meets the wishes and needs of care recipients), and rest and comfort of the patient improve during the stay and are highest towards the middle of the stay. In the last 72 hours the stability decreases. Per patient who dies in a hospice, an average of 3 persons (relatives and/or family) are involved. The authors extrapolate that, in that sense, hospices support about 40,000 persons every year.

As illustrated in Figure 1, geographical access to hospices in the Netherlands is correct as those services are quite well spread over the country with a predominance for the western part and for big cities.[93]

Figure 1 – Geographical repartition of hospices across the Netherlands, 2023



Source: Berenschot report, 2024[75]

5.1.6 Staffing and training

Several disciplines can be involved in the care process but this is often depending on the financial capacity of the organisation[94]: 1) general practitioner; 2) physicians specialised in palliative care or geriatric care; 3) dietitians; 4) physiotherapists; 5) nurses (partly specialised in palliative care); 6) psychologists; 7) trained volunteers; 8) spiritual informal caregivers; 9) social workers…

In HCH and PU, the professionals mentioned above can compose the own permanent multidisciplinary team of the hospice inpatient service. In BHT, the same types of professionals can also be deployed but they come on call (supplemental support). This means that these disciplines can be used in all hospices, but that in professional-driven hospices they are more often permanently linked to the hospice.

Although there is no official specialisation in palliative medicine in the Netherlands, there is a range of training courses that enable general practitioners or specialists, nurses, volunteers and very probably other professional profiles to receive training in palliative care after their studies (continuing education).[95] According to the authors of the Quality of death index, version 2015, there was an adequate number of specialised palliative care professionals, but in some support functions (psychologists, social workers etc), there are shortages. Specialist palliative training is accredited by national professional boards, but this can be inconsistent at times.[63]

Volunteers play an important role in the functioning of hospices inpatient services since their creation, which is, moreover, attributed to them. VPTZ, the umbrella federation for local and regional voluntary associations in palliative care, calculated in cooperation with AHzN (*Associatie Hospicezorg Nederland* - The Hospice Care Netherlands Association) that in 2024 16.692 patients were supported by 14.533 volunteers which corresponds, on average, to a ratio of 1 patient attended for every volunteer involved. About 7 hours of volunteer support were spent in hospices per client each day. Eighty-five percent of the volunteer work consisted of patient care-focused roles.[76, 86]

In BTH, volunteers are on the front line: they manage all services except those provided by GPs and community nurses. Volunteers provide direct patient care and run the household daily between 07:00 -23:00 in shifts of four hours. In some BTH volunteers also have night shifts (23:00-07:00). Volunteers are sufficiently trained and supported to enable them to provide physical care to the best of their abilities and in accordance with their responsibilities. They know how to act in emergency situations.[96, 97]

In the HCH, the role of volunteers is more related to the support to professionals. Those last are in the lead and engage volunteers to help with care tasks and to be present with the patients. Volunteers support patients and their family, assist the nurses and do household-tasks, such as cooking,

laundry, etc. In HCH volunteers also work from 07:00-23:00 in shifts of four hours.[86, 94]

In all hospices, volunteers are also heavily involved in administrative tasks and fundraising.

Textbox 1 – Training of volunteers in the Netherlands[96, 97]

- Training of volunteers in palliative care is perceived to be very important. Initial, as well as continuous training, reflection and supervision are of crucial importance (e.g., communication skills, processing their own bereavement experiences, ability to reflect upon and learn from one's own experiences, role clarity, understanding and reflecting differences in personal values, …).Almost all organisations where volunteers provide care have an education plan for their volunteers By 2023 98% of new volunteers attended introductory training.
- 67% of all volunteers followed further/in-depth training.[76]
- 52% of the courses is provided at a national level, by an academy that is part of the umbrella organisation (VPTZ Nederland).
- The volunteer is knowledgeable and skilled in adapting to the patient, with attention for the four dimensions of palliative care and for collaborating with others. Required expertise and skills as laid out in a specific quality framework are kept up-to-date.
- Volunteers are also educated and trained in self-reflection and in developing effective coping skills.

Coordinators of volunteers (paid by the volunteer organisation) play an important role in running BHT. Apart from coordinating, training, and supervising the volunteers and their work with patients and families, they also have a major role in policy making, public relations, organizing the collaboration and mediation. They play a key role as liaison between the board and the volunteer team. In HCH, there might be a coordinator for the volunteers but in that case, they work in collaboration with a nurse. Their role is so more restricted.[86]

The success of volunteers in the Netherlands is explained by their clearly defined position between families and professionals, the Dutch concept of small-scale community-based hospice, the strength of the federations representing them with a broad range of activities (e.g., advocacy, education, training), and the support of the government. Indeed, the Dutch government has decided to support the training in palliative care and the coordination of volunteers.[86]

5.1.7 Quality of care in hospices and in general

The HOPEVOL study[69] describes hospices' quality of care in an extensive way based on the health patients records. the following dimensions are analysed:

- **Timely referral**: Most care recipients (85%) are admitted on a planned basis. Unscheduled admissions mainly take place from home, more often in HCH than in other types of hospice. Forteen percent od patients dies within 3 days, 80% between 4 days and 3 months, and 6% stays longer than 3 months in the hospice.
- **Continuity of existing care relationships**: In 27 to 37% of the hospices, existing professional care relationships (GP and community nurse) are mapped out when the patient is admitted. Mapping the existing network of informal caregivers (relatives and or family) takes place in only 9%.
- **4-dimensional individual care plan**: the physical dimension was assessed in 97% of cases, psychological dimension was assessed in 75%, the social dimension in 66% and existential isssues are less often mapped (49%).
- **Multidisciplinary consultation** (*Multidisciplinair overleg*, MDO – *Concertation multidisciplinaire d'oncologie*, CMO): hospices using this collaborative process where healthcare professionals from different disciplines come together to discuss and provide input on the care of a patient is score better quality of care than hospices without MDO.

Notably, a potential risk was observed that higher complexity of care needs and situations is not recognized in hospice facilities where integral cooperation through multidisciplinary consultation, systematic problem analysis and joint file management is lacking.

- **Use of EBP guidelines** was found to be globally sufficient
- **Attention to dignity**: this is covered sufficiently according to the authors. Respect, autonomy, empathy, participation and being in good hands are taken care of.
- **Attention to psychological load and carrying capacity**: this is often not done (only 13-18% include this in their health record)
- **Dying at preferred location**: this is not done enough (< 2/3 of hospices take care for this topic)
- **End-of-life care wishes** are described in only 1/3 of the health patient records (e.g., palliative sedation 37%, euthanasia 5%).

The global evaluation of palliative and hospice care in the Netherlands is at the forefront of the palliative care movement. The country's system is open and transparent, and universal coverage is provided in state-of-the-art facilities.[63] According to the authors of the Quality of death index, version 2015, the Netherlands has a high demand of palliative care but also a relatively good provision of palliative care. As so, the gaps between the demand and the provision was one of the narrowest in the world in 2015.[63]

In 2013, a study of Soeters et al has shown that the quality of care in the dying phase is generally of a high level in the Netherlands[98] except that too many people do not die in their desired place. However preferred place of death is often unknown, in only 20% of the cases, making it difficult to say whether most people die in their preferred place.[99] Updated data from the website Palliaweb highlights that most Dutch people want to die at home while the percentage of people who actually die at home fluctuates between 30,5% and 42.6%.[100] Compared to most other European countries, this is a higher proportion. Only 10% of non-sudden deaths in the Netherlands occur in inpatient hospital facilities.

In 2013, transfers in the last three months of life was considered as too high.[98] In 2022, not much is known about transfers but in the last month of life, 32.0% of a study population were admitted to hospital (range 29.4-36.4%).[100]The authors conclude that there was too little anticipating behaviour in healthcare regarding palliative care because too many healthcare workers seemed to have insufficient knowledge about and experience with palliative care. Collaboration and information exchange was also found to be suboptimal in the study. The authors highlighted the importance to detect and signal palliative care problem (situation) as early as possible.

5.1.8 Referrals, multidisciplinary consultation, data sharing and integrated care

To improve the quality of PC studies' findings, the Dutch government, within the NPPZII, emphasized consultation and coordination between care professionals (including volunteers) and transmural collaboration (between community and hospital professionals). As such, health care policy in the Netherlands foresees and finances integrated care between hospitals, hospices, and home care.[94]

So, PaTz groups were set up in the Netherlands. PaTz means palliative care at home. It is a methodology to improve cooperation between front-line health care professionals and expert in PC regarding palliative care at home. During meetings general practitioners and community nurses supported by palliative care consultants, proactively discuss the expected palliative care needs of patients and their loved ones. Patients who qualify for palliative care are entered into a palliative care register.[101, 102] Researchers plead to make the palliative patients the 'director/controller' of his own care. This implies that the patient (or his/her relatives) must be well informed and health literate.

Another opportunity to discuss patients' needs and care and to share knowledge is the transmural PC consultation (*Transitie Consultatie*). This gives the opportunity for primary HCP to consult a specialised HCP (often from a hospital) to receive information, guidance, or practical support. The Dutch legislation foresees this meeting which '*strives for proactive deployment of the care provider specialised in palliative care for every*

patient, family member and his immediate care provider who needs it at the right time and in the right place, appropriately and regularly funded.'[103] In 2022, 36 specialised PC consultation teams provided 4956 transmural palliative care consultations.[104] The 36 teams consist of 317 consultants who use PRADO, a web-based registration system for transmural consultation. Most of the consultants are general practitioners (19%), geriatric specialists (17%) and home care nurses (29%). Most consultations are by phone (90%) and take place during office hours (20% outside office hours).[104, 105] An important characteristic of this care is that the regular care provider maintains the treatment relationship, but with the support of a specialised professional to achieve a better quality of palliative care.

Hospices must connect with (embed in) a network of palliative care. This implies that other palliative care services, besides the hospice care, are always reachable. Hospices are in fact in between the hospital palliative care and the home palliative care. Some plead to choose a geographical scale of operation for the networks in which all care professionals involved in palliative care can (get to) know each other personally. There is an integrated care project aimed at strengthening the front line, but it seems that participation is open-ended so that some regions participate, and others do not. Since the end of 2023, 43 regions (approximately 85% of the Netherlands) receiving a preparatory grant under the ZonMw programme have begun to anticipate and prepare plans to strengthen primary care in all regions and to bring together (where appropriate) existing primary care partnerships and networks. The 43 regions that started with the Preparation Grant can apply for a Follow-up Grant for the implementation phase after the Preparation Grant. The programme aims for national coverage, so that every region in the Netherlands is working to strengthen the organisation of primary care. Regions that did not or could not use the preparation grant can also apply for funding for the implementation phase. The number of participating regions could therefore reach 50 to 55. For this programme, the region is defined as the (sub-region of the) region of the care office. This generally corresponds to the region in which the regional GP organisations operate.

5.2 Germany

5.2.1 Whole context of palliative care services

The development of palliative care in Germany started in the early eighties of the previous century. The first hospital palliative care unit was opened in 1983 at Cologne University Hospital.[106] At the same time in both parts of Germany (East & West), pioneering homecare models for the care of the dying were introduced with very little public and financial support.[106, 107] Indeed, palliative care provision in Germany is characterized by a dual development. Hospice care developed, almost independently of palliative medicine, as a civil society movement. This separate development is still visible in the current organisational structures. While the medical field developed palliative medicine to relieve physical symptoms, the community field developed hospice care aimed at providing psychosocial support. The citizens' led volunteer movement was motivated by an increasing feeling of unease with the denial of death and dying in modern society and the emerging need to invest in end-of-life care. Hospice work, developed as a community movement, depends strongly on volunteer engagement.[108]

The German federal government is currently working to create synergies between these two complementary types of services because without good coordination, limited availability of interventions may not meet the needs of the patient in their four necessary aspects (physical, emotional, social, and spiritual). The ''Act to Improve Hospice and Palliative Care in Germany'' (*Gesetz zur Verbesserung der Hospiz- und Palliativversorgung Hospiz- und Palliativgesetz - HPG*)[109] financially supports the development of specialised in and outpatient PC services and also the cooperation of healthcare professionals.[110] Legal regulations explicitly request communication and networking between hospice, hospital, nursing homes and at home palliative care professionals. However, the efforts of the federal government have up to now failed to ensure complete roll out of palliative care services.[106, 111, 112]

Already since 2007, PC is partly integrated to the German healthcare system legislation, enabling everyone in need of PC to have access to specialised outpatient (ambulatory) palliative care when the federal government had published amendments to social legislation and had created the social code paragraphs §§ 37b SGB V and 132d SGB V on 'Specialised Ambulatory

Palliative Care' (*Spezialisierte ambulante Palliativversorgung – SAPV*).[107, 111, 112] The SAPV law defines the framework of specialised outpatient palliative care (*SAPV*) in the form of recognition of respective operational sites, making it possible to finance specially trained nursing and medical staff duly registered within a palliative team.[106] Up until July 2016, this funding has been regulated by contract between the local health insurance body and the applicant nursing service.[106] Patients with incurable and life-threatening diseases can access a legal entitlement to *SAPV* team if general outpatient PC is no longer able to meet their needs. In accordance with statutory health insurance agreements, *SAPV* teams are available whether the patient lives in a home environment or in a residential care facility.[113]

A representative[b] survey by the German Hospice and Palliative Care Association *(Deutscher Hospiz- und PalliativVerbandes - DHPV*) in 2012 indicated that more than 60% of Germans would prefer to die in their home environment.[114] However the majority die in hospitals and nursing homes. [113] Estimations of the place of death in Germany are : 51.2% at hospital, 23% at home, 19% in nursing or residential home, 4.6% in hospice and 0.6% in any other place.[115] Another study of the same authors (2021) has showed, for a total research sample of 38 954 death certificates, the following distribution of place of death: own residence 21.3%; hospital: 51.8%; palliative care unit: 6.2%; hospice: 4.8%; nursing home: 20.4% and other: 1.5%.[116] So, the repartition has not changed a lot in 6 years, with a same rate of death at hospital and a few less death at home to the profit of hospices and nursing homes.

In Germany, like in Belgium, PC is for people with an incurable, life-threatening condition and their families. [113] In 2021, about 400.000 individuals of the entire German population were eligible for palliative care.[117] Cancer patients make up the majority of those receiving PC but the groups of people with chronic disease or complex geriatric conditions become ever more important. However, there is not yet a successful expansion of PC to these last groups although some good examples already exist: "*In North Rhine-Westphalia, a state-wide palliative care strategy was drawn up for nursing homes. The occupants of nursing homes should have access to the same satisfactory level of palliative care as people living in their home environment or in hospitals*." [113] However the situation in this region is an exception rather the rule. While a number of nursing homes already offer palliative care as part of their care package, other funding agencies and institutions have done little or nothing about the matter. [113] One of the problems is the division of responsibilities in the care of elderly patients. The boundaries between geriatrics and palliative care are not clear-cut. [113] One tricky point is the lack of PC specialist skills of professionals caring for very old persons or those with multimorbidity in the area of communication and in dealing with ethical issues such as the provision or withdrawal of artificial feeding.[113]

In Germany, palliative care services are funded by statutory and private health insurance funds, the civil servants' welfare scheme, statutory and private nursing care insurance funds, employers' liability insurance associations, statutory accident insurance funds, personal liability insurance schemes and/or local authorities (social services departments). In addition, patients may also pay small co-payment.[113]

General palliative care, delivered by primary care suppliers (GPs and nursing care services) and specialists (oncologists, geriatricians, etc.), can meet the needs of most patients requiring PC. Basic qualification in PC is required to deliver general PC in Germany, meaning to have acquired good fundamental knowledge and good basic skills in palliative care.[113] This general PC is often focused on maintaining the physical functions by performing or providing assistance with personal hygiene, dressing or administering medication. The care can sometimes not cover psychosocial needs, information for the family members or social networking. Moreover general PC can struggle to ensure 24-hour pain management or to provide the technical medical services necessitated during the process of dying.[106]

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[b] Interview by telephone of 1044 Germans 18 year or older (https://www.dhpv.de/files/public/aktuelles/Forschung/Forschung_2012_Ergebnisse_DHPVBevoelkerungbefr.pdf)

According to German experts, only a small number of patients with life-threatening medical conditions require specialist palliative care and the involvement of a specialist palliative care team.[113] The types of specialised PC services in Germany is very similar to those in the Netherlands although some differences exist. In Germany, the hospice concept is not systematically linked to residential provision. Many hospices only provide outpatient care that are supported by the government. Another difference is related to the offer in Long Term Care Facilities devoid of palliative units. It would also seem that only 20% to 40% of LTCF staff are trained in palliative care and that collaboration of LTCF with mobile PC teams is only occasional.[95]

Outpatient palliative care at home is provided by various types of mobile team. Those are either hospice-related outpatient volunteers services (*Ambulante hospizdienste - AHD*), which provide support for day-to-day concerns and are an integral part of the hospice sector, or '*Ambulante palliativdienste'* which would not identify themselves as belonging to the hospice sector. This last service is made of a team of healthcare professionals, doctors and/or nurses, who visit patients in their homes and provide care and support to them and their families. Those teams are, in fact, either specialist palliative care nursing services which are slowly disappearing, or 'specialised ambulatory palliative care' *(Spezialisierte ambulante Palliativversorgung - SAPV*), supported by the government.[118]

SAPV teams provide medical and psychosocial care and are supported by the federal authorities to ensure synergy between the two sectors. The main interventions of *SAPV* teams consist in specialist advices on palliative medicine/care and/or the care itself, delivered by nurses or doctors[113] The interventions include the comprehensive management of support based on the patient's individual needs.[113] The involvement of other professional groups such as social workers, psychologists, religious/spiritual counsellors and physiotherapists by the *SAPV* teams is not generally covered by health insurance funds.[113] In 2015, nationwide availability of care by *SAPV* teams was not yet ensured.[113] In 2022, there were 403 *SAPV* teams in Germany.[119]

Hospital PCUs (n=340 in 2022[119]) aim to provide care in crisis situations. The objectives of treatment are to improve or stabilize the condition of individual patients, to improve their quality of life, and/or to discharge them if possible.[113] The length of stay is often short, averaging 9 to 10 days, and in 50% of cases, patients are redirected to home or to an hospice inpatient service. Hospital PC support teams complete the hospital PC offer in Germany. These two types of multi-professional services are issued from the field of palliative medicine. These services consist of teams of doctors, nurses and other professional groups and provide appropriate palliative care in any hospital wards. They care for pain therapy and symptom control, and also manage the patient's discharge from hospital.[113] Hospital-based palliative care units may provide similar services as hospices, but they are typically integrated into large hospital system and offer more specialised medical care.

Hospice inpatient services are derived from the hospice care sector and allows people to stay there until they die. Medical care in inpatient hospice service is provided by general practitioners or physician specialised in PC, often external to the institution. This is the only type of service for which there is an admission criterion linked to life expectancy, which must be less than 6 months. For access to the other types of specialised PC service in Germany, there is no criterion linked to life expectancy. The decisive factor for admission to a residential facility (hospital or hospice) is the patient's choice.

There are only a few day-care centers in Germany, most running as a model service and without regular funding. Day-care services are linked to institutions such as inpatient hospices and palliative care units at hospitals; however, they may also operate independently. The primary aims of these day-care services, in which patients spend up to five days per week, are maintaining patients' autonomy, improving patients' quality of life, and supporting family caregivers by granting them "respite care".[120]

Germany stands out for having a longer duration of palliative care follow-up than other European countries, which is an indication of awareness to the concept of palliative care not linked to life expectancy. It is possible that the compulsory nature of PC courses during the training of caregivers as well as the number and role of volunteers in the palliative care sector plays a role in this public awareness about palliative care and end-of-life.

Various interest groups and specialist associations, such as the German Society for Palliative Medicine (*Deutsche Gesellschaft für Palliativmedizin - DGP*), associations of volunteers such as the German Hospice and Palliative Care Association (*Deutsche Hospiz- und PalliativVerband - DHPV*) and the Federal Association of Hospice Associations in Germany (*Bundesarbeitsgemeinschaft Hospiz e.V - BAG Hospiz*), as well as self-help organisations (that represent the interests of individual patient groups or families) have played a significant role in public discussions, research activities and endeavours to advance the field of palliative care in Germany. Many other association are also involved: the German Cancer Society (*Deutsche Krebsgesellschaft - DKG*); the German Foundation for Hospice and Palliative Care (*Deutsche Stiftung Hospiz und Palliativ Versorgung - DSHV*); the German Medical Association; the State Chambers of Physicians (associations of Statutory Health Insurance Physicians), the umbrella organisations of welfare associations and several organisations for volunteers. Some of these interest groups set important standards. Yet the systematic involvement of all the relevant interest groups in development and decision-making processes has proved the exception rather than the rule across the board in the field of palliative care.[113]

5.2.2 Description of hospice in- and out-patient services

The first hospice in Germany was founded in 1986 by Pastor Otto Türks in Aachen.[106] Then the number of hospices for palliative care increased substantially over time. From 1996 the number of ambulatory hospice (outreach & support at home) services in Germany has steadily increased approximately fourfold to reach the number of 1500 in 2016.[106] The services provided in the inpatient hospice services[113] are governed by Art. 39a of the German Social Code, Book V (*SGB V*).

In Germany, hospice care is provided by specialised hospice facilities or hospice services that offer inpatient or outpatient care for patients with life-limiting illnesses. There are significant differences between hospice services concerning the type of interventions. Certain inpatient hospices focus on complex medical care. This type of hospices delivers comprehensive palliative care, including pain and symptom management, emotional and spiritual support, and assistance with activities of daily living. Other hospices (more specifically those ran by a small professional group and more volunteers) provide more psychosocial care but less medical or nursing care.[113] In Germany, the majority of inpatient hospice care units are managed by a professional administration, with a regular CEO. However, a few are volunteer-led.[118]

Outpatient hospice services (*ambulante hospizdienste*) provide volunteer services with primordially psychosocial care. Globally, the main task of hospice outpatient services is the support provided by volunteers to patients and their families.[113] This support is mainly delivered at home but also in hospitals, care homes or inpatient hospices.[113]

Inpatient hospices (*stationäre Hospize*) are stand-alone facilities, not connected to a hospital or elderly home, which ensure that people with incurable, life-threatening diseases receive palliative care where such care cannot be provided in the home environment and do not require hospital treatment.[113] Inpatient hospices are institutions with a family-like atmosphere, which are generally part of a networked care structure within the regional health and social welfare system. Patients usually stay there until the end of their life.[118] Inpatient hospices do not have physicians on their payroll.[118] Medical care is provided within the contractual healthcare system by an external accredited GP or by a physician with a sub-specialisation in palliative medicine.[113] In 2022 Germany counted about 250 hospice inpatient hospices for adults and 19 inpatient hospices for children, adolescents, and young adults.[119]

5.2.3 Financing of hospices

Certified hospice services are eligible for reimbursement from the health insurance system but inpatient hospices have to provide 5% of costs from other sources, such as fund raising.[118] Palliative care inpatient services have the option of applying for recognition as 'defined special service' and charging per diem rates.[113] However, the political will is for all palliative care units to charge flat rates per case. There is also regular financing available for palliative care and hospice networks, detailed in §39d of the *Fünftes Buch Sozialgesetzbuch - Gesetzliche Krankenversicherung*.[121]

It is frequent that many palliative care initiatives are unable to cover their costs. There are for example no regulation covering the psychosocial care. Payment for many such services is currently inadequate or even non-existent.[113] This implies that a holistic palliative care system is often only able to operate by virtue of civic involvement through volunteering, or through donations and the work of foundations. However, the wages of professional volunteer coordinators and the related functional cost are reimbursed by sickness funds, based on the number of patients supported. Volunteer training is a prerequisite for reimbursement of staff costs by the sickness funds.[122]

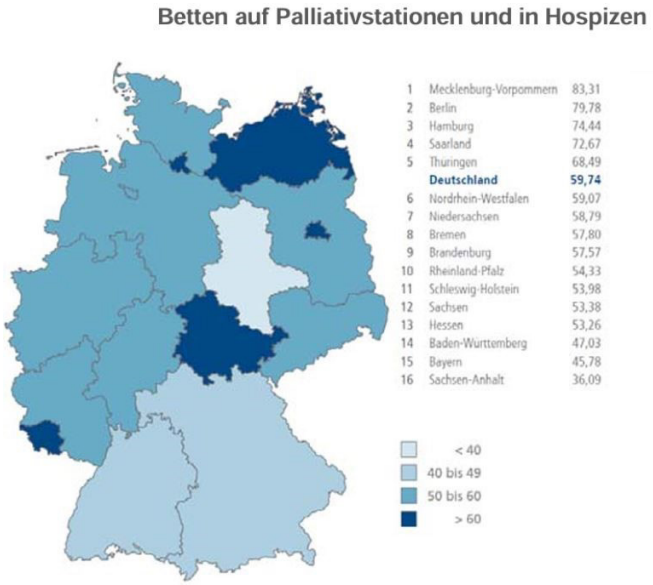
5.2.4 Access to hospice in- and out-patient services and target population

Patients with a life-limiting illness can be referred to hospice services by their GP, ambulatory specialist doctor, or by a doctor of the hospital.[123] Outpatient hospice services may provide care for patients who are receiving palliative care at home but require additional support. Life expectancy is not a determining criterion for access to palliative care in Germany. Palliative care is provided to individuals who have a life-limiting illness, regardless of their life expectancy. There is however one exception, admission to an inpatient hospice requires a physician 's statement that the life expectancy of the patient is six months or less.

Patients in Germany generally have the freedom to choose between receiving palliative care in a hospice or in a hospital setting. In theory, both options are available and can be chosen based on the individual needs and preferences of the patient and their family.[113] The patient and their family are expected to work closely with their healthcare professionals to determine the best option for their particular situation.[123] The main criterion for choice of stay in inpatient service is the patients' preferences.[116]

Palliative care hospices in Germany are generally well spread across the country, although their availability may vary depending on the region. The availability of palliative care hospices is influenced by a variety of factors, such as population density, funding, and local healthcare infrastructure.[124] There are considerable gaps in provision in rural areas. This is particularly true in the case of outpatient palliative care. The catchment area for outpatient service professionals in rural areas can be enormous.[113] The network of PC service professionals in the field of palliative care is constantly expanding, but has not yet reached all parts of Germany, and its density varies from one region to another.[113] But this has improved considerably in the last 10 years, and at present the WHPCA Atlas rates Germany as stage 4b (advanced integration of palliative care in the health care system).[125] There is a directory of PC services including more than 3,000 hospice and palliative care services across the country. This guide is available in nine different languages. (see: https://www.wegweiser-hospiz-palliativmedizin.de/de)

Figure 2 – Geographical repartition of hospices across Germany, 2016



Legend: Beds per million citizens in Germany Source: figure retrieved from Scheiner et al. 2016 [126]

5.2.5 *Profile of patients admitted in hospice in- and out-patient services*

According to recent studies, the most common underlying diagnosis for outpatient palliative care was cancer (55%), followed by heart failure (16%) and dementia (8%).[119, 127] There are only small differences in population characteristics between hospitals and hospices.[116]

Staffing and training

The following disciplines are involved in the palliative care provision in Germany[128]:

- Physicians (GPs & specialists)
- Nurses (basic & specialised
- Social workers
- Psychologists
- Physiotherapists
- Occupational therapists
- Art therapists/Music therapists
- Pastoral informal caregivers
- Relaxation specialists
- Chaplains

The palliative approach with its goals is taught and promoted at all levels of training for professional service professionals in Germany. Since 1997, various curricula in palliative care were implanted for different health professions. Qualifications for those working in palliative care are an established feature of basic and advanced training schemes: for example, the curriculum 'Palliative medicine curriculum for medical students and doctors practising palliative medicine' *(Palliativmedizin Für Medizinstudenten und Ärzte*).[113] Also the Art. 3 of the Nursing Act (*KrPflG*) has referred to palliative care acts as being part of the training curriculum since 2003. The compulsory nature of PC courses during the training of professionals plays a role in awareness of professionals and the public to PC. By 2021, 14 620 physicians had acquired a qualification in PC.[119] The threshold of 1 doctor specializing in PC per 100,000 inhabitants has been reached in Germany.[95] Palliative care courses are integrated into the curriculum for medical students and 11 German universities host a chair for palliative medicine.[107]

The number and role of volunteers in the palliative care sector is important in Germany, as is public awareness of palliative care.[129] In 2019, it was estimated that volunteers support hospice work in 1400 outpatient hospice services.[107] In 2022, more than 120,000 people were involved on a voluntary, civic, and full-time basis and support the work for seriously ill and dying people.[119] Palliative care and hospice volunteering today has become firmly established in Germany as an integral part of the care of severely ill and dying patients. The volunteers take on a wide range of practical support services which are intended to make it easier for those affected to cope with day-to-day concerns.[113] The work of volunteers is coordinated by a professional coordinator, funded by the authorities. He/she supports and assists the volunteers in their work and may take responsibility for coordinating hospice outpatient volunteers services and any other types of palliative care services involving volunteers.[113] In most cases, volunteers are organised in outpatient hospice service *(Ambulante hospizdienste,- AHD)*. Volunteers are trained by coordinators. Coordinators need to be well trained in care, social work, coordinating and need to have at least 3 years of working experience.[122]

Charter and legislation govern the role and training of volunteers. The Hospice and Palliative Care Act (*Hospiz- und Palliativgesetz*) clarifies that volunteering is an important part of palliative care: for example, nursing homes and inpatient hospices need to have a formal collaboration agreement with a volunteer's organisation. In 2012 the 'Charter for the Care of the Critically Ill and the Dying in Germany' (*Charta zur Versorging von Schwerstkranken und Sterbenden*)[130], a national joint action led by the DGP, the DHPV and the German Medical Association, and supported by almost 1000 organisations and institutions (15.000 individuals involved), was published. This charter acknowledged that volunteering is an expression of

citizen engagement and proof of solidarity in society. It also acknowledged that volunteering is a core element of hospice work and care for patients and their families.[122]

Volunteers provide psycho-social support for patients and their families without hierarchical distance and can assure a patient centred and multidisciplinary approach. They also offer bereavement services for which they are often specifically trained. Training programmes for volunteers have been developed and are generally accepted as necessary to ensure good quality of care. A total of 100 to 120 hours of training is recommended. Training should focus on personal motivation, qualification and provide work experience but attention is also given to 'help the helper'. Volunteers are also educated in documenting their work, legal regulations, insurance, and public relations.[122]

5.2.6 Quality of care in hospice services and in general

The quality of palliative care in Germany is closely monitored and evaluated through a variety of methods to ensure that patients and their families receive high-quality, compassionate care that meets their individual needs and preferences. The evaluation of hospice care in Germany is guided by legal regulations and standards. The Hospice and Palliative Care Act[109] sets out specific requirements and quality criteria for hospices and palliative care services.[131] It states: "*nationwide standards must be set for the scope of services and the quality of the services eligible for subsidies*."

The S3-Guideline Palliative Medicine (1st part 2015 and 2nd part 2019) provides evidence and consensus-based recommendations for best practice in palliative care for patients with incurable cancer.[c107]

Certifications and accreditations are methods to ensure the quality of care.

- Hospices can seek certification from the statutory health insurance funds. Certification involves an assessment of various aspects, including personnel qualifications, interdisciplinary collaboration, patient care processes, documentation, and infrastructure. Certified hospices are eligible for reimbursement from the health insurance system.
- The *DHPV* accreditation programs ensures that hospices and other palliative care initiatives meet certain quality standards[d].[132] The *DHPV* (*Deutsche Hospiz- und PalliativVerband* - German Hospice and Palliative Care Association) is an umbrella organisation representing hospice and palliative care professionals, professionals and volunteers in Germany. The accreditation program evaluates the quality of care provided by the hospice or provider, including the competence of the staff, the quality of the facilities, and the level of patient and family involvement in care.[118, 132]
- Th *DGP* certification is available for palliative care units and for palliative care consultation services and is well acknowledged (official certification with the Clarcert agency).[118] The *DGP* is the *Deutsche Gesellschaft für Palliativmedizin*, meaning the German Society for Palliative Medicine. This is a scientific and medical society with more than 6000 members involved in care services in varying areas[107] that concentrates on advancing the scientific knowledge and medical practices in the field of palliative care.[118] It also promotes education in palliative medicine, providing support and training for healthcare professionals working in palliative care.[133]
- The certification of oncology centers by the German Cancer Aid and the German Cancer Society includes a mandatory part concerning palliative care connected to funding.[118]

However there is an absence of criteria by which to evaluate the quality of the PC networks.[113]

[c] A short 2015 version is available in English: https://www.leitlinienprogramm-onkologie.de/fileadmin/user_upload/Downloads/Leitlinien/Palliativmedizin/Guideline_Palliative_Care_Short_Version.pdf

[d] The handbook of evaluation can be found at https://www.dhpv.de/files/public/broschueren/2020_BRH%20Stationaere%20Hospize_200115.pdf

Patient satisfaction surveys are also used to evaluate the quality of palliative care in Germany. These surveys gather feedback from patients and their families about their experiences with the care they received. The results of these surveys are used to identify areas for improvement and to develop strategies to enhance the quality of care. The instrument HOPE (Hospice and Palliative Care Evaluation - *Forschung Hospiz- und Palliativerhebung*) is a documentation and quality assurance instrument which was been undergoing a continuous process of development and validation since 1999, and which conducts an annual benchmarking study of participating institutions.[134]

There is also a patient data register kept by the *DGP* which collects data from an annual sample. This National Hospice and Palliative Care Register[e] collates patient-related data from the day-to-day provision of hospice and palliative care across regions, professions and sectors at least once a year for a minimum random sampling period of 3 months and a sample size of 30 patients.[135] The *DGP* has however suspended operations of the National Hospice and Palliative Care Register until further notice. Most important reason is that the *DGP* board has decided to develop a new national hospice and palliative care register. The delivery and reading of register data was only possible until September 30, 2023. However, the data available on outpatient care (*SAPV*) from the *Gemeinsamer Bundesausschuss*, allows to provide three-yearly reports to the ministry of health (though the last published report was from 2017).[136] There are also a few evaluation reports of the *Bertelsmann Stiftung* from 2015.[137]

5.2.7 *Referrals, multidisciplinary consultation, data sharing and integrated care*

The government promotes the setup of palliative care networks. Over the last years the Ministry fostered the establishment of regional hospice and palliative care networks through a pilot project, and networks could present themselves to the public on the Ministry's website.[120] Regional palliative care and hospice networks receive financial support from the federal authorities. But one of the difficulties in achieving balanced collaboration is the regionalisation of healthcare in Germany. It must be stated that, as the German regions (*Bundesländer*) are quite independent, some regulation may not apply or in a slight different way in certain areas. Due to this fragmented system of care delivery with its accompanying databases, comprehensive statistics about the present use of and the future demand for palliative care services in Germany are sparse.[117]

The German ''Evidenced-based Guideline: Palliative Care for Patients with Incurable Cancer'' defines the integration of already existing network structures in the field of hospice and palliative care as prerequisite to high quality specialised outpatient palliative care.[138] There has been an update in 2020 (*Erweiterte S3-Leitlinie Palliativmedizin für Patienten mit einer nicht heilbaren Krebserkrankung 2020*).[139]
Nursing homes and inpatient hospices need to have a formal collaboration agreement with a volunteer's organisation and *SAPV* teams work closely together with other service professionals such as community-based doctors, nursing services, hospitals, residential care facilities, hospice services and pharmacies.[113]

[e] See more: https://www.hospiz-palliativ-register.de/

5.3 United Kingdom

5.3.1 Whole context of palliative care services

The modern PC and hospice movement in the United Kingdom (UK) (and in fact worldwide) started in 1967 with Dame Cicely Saunders opening St. Christopher's Hospice in South London. Holistic care was a core element in palliative care from the beginning and has developed into a full medical and healthcare multidisciplinary specialism that not only focuses its expertise on symptom management of life-limiting illnesses but also in the holistic provisions of comfort and supports in psychological, social, and spiritual care at the end of life.[140]

Between 2004 and 2007, the "National Health Service (NHS) End of Life Care Programme" has contributed significantly to the rollout of programmes such as the Gold Standards Framework, the Liverpool Care Pathway for the Dying Patient, and the Preferred Priorities for Care. Before the launch of that program, research showed that most people wanted to die at home in UK yet most in fact died in hospital. The underlying reason for this mismatch was that health and social care services struggled to respond satisfactorily to people's varying end of life care needs. The creation of the National End of Life Care Programme in 2004 was designed to improve this situation. The National End of Life Care Programme was set up to offer patients nearing the end of their life high quality care and choices about where to die. Objectives were reducing the number of unnecessary emergency admissions and improving the skills of the workforce. The reviewing of the National End of Life Care Programme 2004-2007 showed that it has helped to raise the profile of end-of-life care services. But it has also showed that much more needs to be done there are examples around the country of excellent end of life care, but the best must be spread to the rest. The success depends on better organisation and collaboration, effective use of resources and good communication between commissioners and professionals. Above all, care must be focused on the individuals and their caregivers. In particular, the evaluation has alerted primary care staff to the centrality of their role in establishing high quality, well-coordinated services.[141]

This is why the End-of-Life Care Strategy 2008 of the UK government (department of Health) was then set out to improve end-of-life care for all individuals in UK, based on a whole systems approach. The aim of this strategy is to promote high quality care for all adults at the end of life.[142] The Strategy promotes a 'vision for a good death' that is 'irrespective of age, gender, ethnicity, religious belief, disability, sexual orientation, diagnosis or socioeconomic status'.[46] The strategy emphasizes the importance of person-centred care, coordination between healthcare professionals, and support for families and caregivers.[142] It starts with the will to change attitudes to death and dying in society and the need of palliative patients to have their needs assessed, their wishes and preferences discussed and an agreed set of actions reflecting the choices they make about their care recorded in a care plan, available to all who have a legitimate reason to access it (e.g. out of hours and emergency services).[142] In addition, the strategy supports the work from the Marie Curie Cancer Care Delivering Choice Programme demonstrating the effectiveness of establishing a central coordinating facility providing a single point of access through which all services can be coordinated. A central register of people approaching the end of life allows them to receive priority care. The End of Life Care Strategy 2008 also highlights the importance of 24/7 services provision to avoid unnecessary emergency admissions to hospital and to enable more people at the end of their life to live and die in the place of their choice.[142] All those strategic points require a review of the availability and quality of end of life care services in the different settings, as well as the involvement of families, close friends and informal caregivers of people approaching the end of life.[142]

The "Marie Curie Delivering Choice Programme" (DCP), run by Marie Curie Cancer Care, was commissioned in 2012 to review and redesign palliative and end of life care in a part of Scotland through the "Reshaping Care for Older People" programme. The DCP used an evidence based approach to help palliative patients be cared for in their place of choice, by assessing gaps in local service provision and developing and implementing new initiatives to address these gaps such as end-of-life care coordination centres, an out-of-hours telephone line and discharge in-reach nurses.[143, 144] This "Choice in End of Life Care Programme" promotes greater choice and personalization in end-of-life care. It aims to enable individuals to express

their preferences and make decisions about their care, including the option to receive care in a hospice or at home.[145]

According to the 2008 Strategy, the health and social care workforce can be segmented into three broad groups in relation to end of life care. Staff who spend the whole of their time caring for those at the end of life, those who frequently deal with end-of-life care as part of their role and those who care for people at the end of life infrequently. At all levels, professionals need to have the necessary knowledge, skills and attitudes related to care for the dying to successfully improving end of life care. The training of health and social care staff for whom end of life care is only one aspect of their work, should include the capacity to identify those who are approaching the end of life, to communicate with them and to deliver optimal care. To improve quality structures and processes can be measured through self-assessment by organisations against the quality standards.

The 2008 strategy set up the NHS Choices website which contains information to answer any questions from patients, caregivers, commissioners, clinicians, service professionals, researchers, and policy makers. Information on place of death is available through the Office for National Statistics and outcomes of end-of-life care can be monitored through surveys of bereaved relatives, national audits, and regular reviews of complaints. Many of the improvements envisioned can be achieved by better use of existing health and social care resources. It is likely, for example, that at least part of the additional costs of providing improved care in the community and in care homes will be offset by reductions in hospital admissions and length of stay.[142]

Since a broad partnership of national organisations with a deep commitment to improving end of life care in UK came together to publish the "Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020", the Partnership has been enlarged and pursues the joint commitment to make sure that person centred care is reflected in everything done in PC and EOL care throughout UK.[146] The Frameworks (2015-2020 and 2021-2026) are used to benchmark services, develop local strategies and plans, support business cases and help shape learning and development offers.[146] While the NHS Long Term Plan commits to improving personalised palliative and end of life care for people of all ages and to address health inequity, a guide (of Local Government Association and Association of Directors of Adult Social Services) emphasises the role of councils in this important area and a Government's white paper on Integration and Innovation signals support for an integrated approach to health and care. This integrated, place-based system approach is ideal for the continuing efforts to drive improvements in palliative and end of life care and must be focused around the individual and those important to them, and has to be locally led and delivered.[146] The Framework 2021-2026 is based on 8 foundations: (i) personalised care planning; (ii) shared record; (iii) evidence and information; (iv) involving, supporting and caring for those important to the dying person; (v) education and training; (vi) 24/7 access; (vii) collaboration between people with personal and professional experience of PC/EOL; and (viii) leadership of the health and wellbeing boards.[146]

Since 2022, "The 2022 Health and Care Act" introduced new legislative measures that aim to make it easier for health and care organisations to deliver joined-up care for people who rely on multiple different services, building on earlier recommendations by NHS England and NHS Improvement.[147] Among other legislations, this act states a legal duty on Integrated Care Boards (ICBs) to commission palliative care services.[148]

Palliative care services (including hospice services) are typically regulated and overseen by general healthcare regulatory bodies that cover a broad range of healthcare services. The NHS, which is the publicly funded healthcare system, primarily provides palliative and hospice care services. The NHS has established guidelines and frameworks for palliative care to ensure consistency and quality across the country.[f] The Care Quality Commission (CQC) is responsible to assess the quality of the PC services. This commission notably bases the PC services inspections on quality standard of the National Institute for Health and Care Excellence

[f] See more here: https://www.goldstandardsframework.org.uk/

(NICE).[149]The NICE guideline on end of life care delivery for adults published in 2011 and updated in 2021 concerns adults (aged 18 and over) who are approaching the end of their life. This includes people who are likely to die within 12 months, people with advanced, progressive, incurable conditions and people with life-threatening acute conditions. It also covers support for their families and caregivers. It includes care provided by health and social care staff in all settings.[150] Another NICE quality standard covers care of dying adults in the last days of life.[151]

Also in UK, palliative care is provided through both specialist and generalist services. Specialist PC services are either multidisciplinary team of National Health Service (NHS) or hospice staff with the requisite qualifications, expertise and experience. Generalist PC services are all other health professionals, supported by specialist teams.[152]

Settings where PC are delivered in UK are[153]:

- Hospitals: short term PC are delivered until a discharge plan is in place. Depending on the condition and the needs, support is overseen either by specialist teams or a single nurse. PC teams arrange for patients to be transferred to receive PC in hospices, care homes or at home.
- Hospices : Hospices are similar to residential care homes in some ways. They deliver palliative nursing and rehabilitation, but people do not have to reside there permanently – they can attend for the day then return home.
- Nursing home: Not all residential nursing homes can provide palliative care; only those with specially trained staff. For those who already live in those nursing homes, remaining there to receive end-of-life care is a more comfortable option than having to move to a hospital ward.
- Day care : Palliative day services are for people with a complex or life-limiting illness, and need their symptoms controlled. The staff provides individualized, holistic care, that promotes independence and rehabilitation, improves self-worth, and ultimately enables the best quality of life for patients and their families. Relationships are at the heart of day services. Day services provide specialist palliative care within a group context, where meaningful relationships are paramount. day services offer the opportunity for regular review and assessment of the patient's condition, and sets holistic goals that address physical, psychological, social, and spiritual needs. Day services provide proactive care, with the specific aim and outcome of preventing crises, enabling rehabilitation, and developing self-management strategies. Day care services across the country vary in the structure of their service, staffing, and provision.154
- Home: Palliative home care enables individuals to remain in their own homes to receive end-of-life care. Nurses, specially trained in palliative nursing, will move into the home of the person they are responsible for looking after to provide round-the-clock support. It is referred to as hospice at home. A trained palliative nurse (not related to an hospice) can also perform home visits at arranged times of the day and even overnight. Homecare visits can be used to provide breaks for family members or other professionals, or to assist with personal care or continence care, for example.

In 2019, Firth et al published a list a criteria allowing to distinguish the different types of specialised PC services in UK. Figure 3 shows those criteria. The authors remains careful in the appropiateness to spread those criteria to other countries than UK but suggested to use it as a basis to develop such list of criteria in other countries. Characteristics such as holistic care, training in specialist PC and use of multidisciplinary teams in delivrey of care are not considered as differentiating criteria because there are core to the definition of specialised PC.[155]

Figure 3 – List of criteria allowing to distinguish different types of specialised palliative care services in the United Kingdom

Table 3. Final agreed criteria to define models of palliative care.

Sixteen criteria which reached consensus on Rounds 1 and 2 of Delphi survey	
1	Setting of care (inpatient hospital, inpatient hospice, home based, etc.)
2	Type of care delivered ('hands on' or advisory)
3	Size – measured by number of referrals accepted annually
4	Number of disciplines delivering the care
5	Mode of care ('face to face', telephone, or other remote delivery)
6	Number of interventions available
7	Whether 'out-of-hours' referrals are accepted
8	Whether 'out-of-hours' care is available to patients already known to the service
9	Time when is 'out-of-hours' care available?
10	'Out-of-hours' mode ('face to face' or advisory)
11	Type of 'Out-of-hours' provision ('hands on' or advisory)
12	Extent of education/training provided to external professionals
13	Whether outcome and experience measures are used in the service
14	Whether standard bereavement follow-up is provided?
15	Whether complex grief follow-up is provided?
16	The primary diagnosis of those patients receiving care (cancer/non-cancer)
Four further criteria included into final set following testing/feedback from structured interviews	
17	Is service a publicly funded or voluntary funded service?
18	Patient or family self-referrals or not?
19	Whether there are standard discharge criteria?
20	Purpose of care provided

Source: Figure retrieved from Firth et al., 2019.[155]

In the UK, volunteers are inextricably linked with the history and development of hospice care. Most of the 'independent' hospices were founded by volunteers. There is a strong link between the volunteering movement and the sustainability of voluntary sector hospices. Volunteers work hard to the awareness raising of the general population on the vision and aims of the hospice movement and the needs of palliative care (e.g., solving taboos and improving knowledge).[156] Volunteers and volunteering are not defined in the law within the UK. Some people perceive this as a positive situation (volunteering can flourish without restrictions) while others see this as a negative situation (denial of volunteer rights). There are however several rules and regulations for hospices (a regulated framework) with which volunteers must comply. But regulation regarding volunteers remains quite sparse.[156]

Two types of nursing services deserve to be highlighted for their profile: the Macmillan and the Marie Curie services. Macmillan nurses are specialist nurses that work in different areas of cancer care and treatment. They work in hospitals, hospices and in the community. While some of them are specialised in supportive care during cancer treatment, others are PC nurses. Some palliative care nurses are based in hospital. They may be called a palliative care clinical nurse specialist. They care for hospital inpatients. They are experts in managing symptoms and medications. They work with members of the multidisciplinary team to help plan care in hospital. They also refer patients to the palliative care team in the community at discharge. Other specialist palliative care nurses are based in the community and visit patients at home. They work as part of a community palliative care team and may be connected to a hospice. Community palliative care nurses work with the GP and district nursing care team to give them specialist advice on treating symptoms, medicines, emotional support, or any other support needed but they do not usually give hands-on physical nursing care in the same way as hospital ward nurses or district nurses in the community. Access to Macmillan nurse requires a referral by a doctor or another nurse.[157]

Marie Curie nurses offer specialised palliative care, whatever the illness. They provide one-to-one nursing care and support overnight at home, usually for eight or nine hours. In some areas, it is possible to be cared for a shorter period, or during the evening or daytime, as well as care at very short notice in a crisis. Marie Curie nurses deliver hospice care in partnership with the NHS. The type of service provided by the nurses vary in each area, according to what support the local NHS trust has decided. So Marie Curie nurses provide care and support for people with any terminal illnesses, including terminal cancer, towards the end of their lives.[158]

In 2008, the governmental EOL care strategy states that it is impossible to calculate the cost of end-of-life care in the UK because of the difficulty in defining exactly when end of life care starts and that costs are depending on different government departments such as *Attendance Allowance* and *Disability Living Allowance*. However, key elements of expenditure can be

identified through data on hospital admissions; hospices and specialist palliative care services; community nursing services; and care homes.[142]

The following funding mechanisms were identified:

- NHS: Hospice and palliative care services provided by the NHS are generally funded through general taxation and the NHS budget.
- NHS Continuing Healthcare: In certain cases, individuals with complex healthcare needs, including those requiring palliative care, may be eligible for NHS Continuing Healthcare funding. This funding covers the full cost of care, including accommodation, for individuals who meet the eligibility criteria.[159] To get NHS continuing healthcare you must have ongoing significant physical and/or mental health needs and having taken account of all your needs, the main aspects or majority part of the care you need must be focused on addressing and/or preventing health needs.[160]
- Personal Contributions: While the NHS and charity (donations) cover the majority of costs associated with palliative and hospice care, there may be instances where individuals are required to contribute to certain aspects of their care. This can include charges for non-essential amenities or additional services that are beyond the standard level of care provided.[161, 162]
- Social Care Funding: Social care services, including palliative care provided outside of a hospice setting, may involve separate funding arrangements. Local authorities are responsible for providing social care services, and individuals may be assessed for their eligibility and means-tested contributions towards the cost of their care.[163]

It is important to note that specific funding arrangements and eligibility criteria can vary across the UK, as healthcare systems are devolved to each part of the UK (England, Scotland, Wales, and Northern Ireland). Additionally, individual circumstances and the availability of services in a given area can also impact the financing of palliative care.

Establishment of coordination centres/facilities; provision of 24/7 home care services; improved ambulance transport services for people near the end of life; additional specialist palliative care outreach services (to provide advice and care for non-cancer patients and to increase input into care homes and community hospitals); and improved education and training of existing staff in care homes, hospitals and the community should also be included in the budget to be planned for the development of improved PC in UK.[142]

Evidence from the UK shows that home is the most frequently chosen place to die, despite variations across conditions and age groups. Inpatient hospice is usually the second most frequently chosen place to die. Older people are more likely to choose inpatient hospice than their younger counterparts although currently they are the group least likely to die there.[164]

In 2022, hospital is the most common place of death (43.4%) although more than half of deaths (56.6%) occur either at home (28.7%), in a care home (20.5%), a hospice (4.7%) or in other places (2.6%). The percentage of people who died at home remains higher (28.7%) than seen before the COVID-19 pandemic (24.4% in 2019). 6.2% of people who died had 3 or more emergency admissions to hospital in their last 90 days of life, lower than every other reported year (since 2015).[165]

5.3.2 Description of hospices

In 1967 Dame Cicely Saunders opened St. Christopher's Hospice in South London, the first modern hospice worldwide. It was a building for 54 patients with 16-bed residential wing for the elderly and a planned bereavement service. Home Care started two years later but was planned from the beginning.[166] The focus of the early hospices was on excellence in the holistic palliative and end-of-life care of patients with cancer.

As described for other countries and in line with the worldwide missions of PC services, hospice services in UK offer wide-ranging, personalised care to improve the quality of life and wellbeing of people with a life-limiting or terminal illness. People who are cared for by a hospice in UK may have cancer or a condition other than cancer. Care is provided by a multi-disciplinary team of different professional staff and volunteers. As well as taking care of people's physical needs, they also look after their emotional, spiritual, and social needs. Hospices also support informal caregivers, family members and close friends, both during a person's illness and during bereavement.[167]

At present, hospice care is well established in the UK with 220 residential institutions in 2018[168] and many palliative day-care centres and home care support teams. In 2018, around 95% of inpatient beds for specialist palliative care were hospice-led. Eighty-eight percent of inpatient hospice services were charitable organisations-led and 12% were NHS units. About 60% – 75% of community palliative care is delivered by hospice organisations.[152] According to the database of HospiceUK[g], the main charity for hospices in UK, in the year 2022-23, 18% of hospices' total service activity was delivered in an inpatient unit and 55% of hospices' total activity was delivered at the person's place of residence. In the same period, hospices across the UK provided PC to 300 000 people.[169] In addition, 330 000 appointments were provided during the same year to patients' families, friends and informal caregivers, including counselling and bereavement support.[169]

Hospices offer different kinds of services in the UK[46, 152, 153, 169]:

- inpatient service : patient stays in a bed in the hospice for a period of time. This type of service offers a calmer environment in which to receive the medical support required. In 2022-2023, 600 000 days and nights were spent to deliver inpatient PC. Pretty much all hospices in UK offer inpatient service.
- patients' home services : a member of the hospice staff or a team offers companionship and practical support services for those living at home. Informal caregivers specially trained in palliative nursing are responsible for looking after to provide round-the-clock support. In 2022-2023, 880 000 visits were made by specialist PC nurses and doctors to hospice patients at home and 910 000 visits were made by generalist healthcare staff including nurses, healthcare assistants, social workers and informal caregivers.[h] Around 75% of the hospices provide patients' home service.
- outpatient service : a patient living at home travels to the hospice for care. Consultations services and day therapy services are examples of this kind of services. Day therapy services deliver palliative nursing and rehabilitation to people which do not reside there permanently. The patient attends for the day then returns home. In 2022-2023, 820 000 outpatient appointments were made by hospices for physiotherapy, counselling and other support services. Around 85% of the hospices provide day service.
- community based services include activities in community hubs such as a village hall or library and outreach work.
- online services
- education and local service developments, including provision of information, support, education and training to informal caregivers.

Common interventions provided in hospices in the UK are pain and symptom control, wound care, nutritional support, intravenous therapy (in most cases), assistance with daily activities, psychological support, physiotherapy and rehabilitation (in most cases), end of life care planning, respite care, spiritual care, and often also bereavement support.[167] Social support including financial advice can also be included as well as provision of specialist occupational therapy, and complementary therapies such as massage and aromatherapy. The specific medical and non-medical technical interventions offered can however vary among hospice services.[167] And hospices provide 24 hour interventions, for example, in case of terminal care or emergency care.[167]

5.3.3 *Financing of hospices*

Hospice care is free for people who use services. Hospices in England receive a variable proportion of their funding from government, and the rest comes from other sources, primarily fundraising. The proportion of statutory funding received by a hospice on average covers a third of their costs. However this varies considerably depending on local commissioning decisions; many hospices receive significantly less than a third.[167] Statutory

g Data from a survey led by Hospice UK including 80% of the 204 Hospice UK members as respondent.

h Data from a survey led by Hospice UK including 80% of the 204 Hospice UK members as respondent.

funding now covers 37% of total charity expenditure on palliative care services – or approximately £350 million per year. While Government funding has slowly increased over the past seven years, as a proportion of total expenditure it has largely remained static.[170] The UK government has sought to promote volunteering (e.g., the 'Big Society' initiative (2010) that intended to increase levels of volunteering). However, the necessary funding to facilitate this remains too small.[156]

In addition to the funding from the government, the other two-thirds are covered by the local community (donations, legacies, and trading). This is the reason why charity funding is inextricably linked to palliative hospice care in the UK. According to Hospice UK database, it costs £1.6 billion each year to run the hospices in the UK. Hospices raise over £1.1billion of this through fundraising and less than £0.5billion comes from government funding.[171] Access to hospice in- and out-patient services and target population

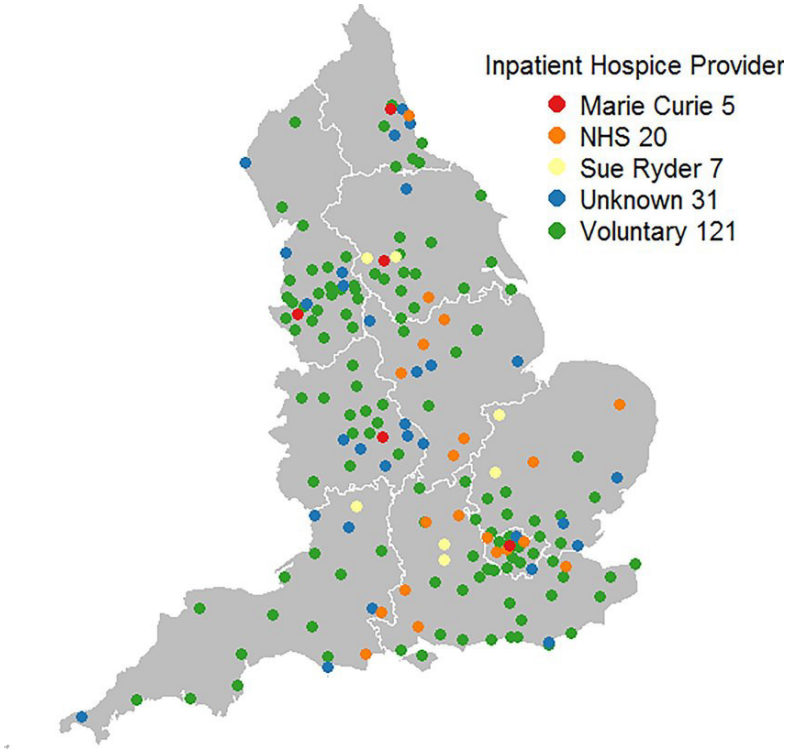
Hospices in the UK are generally accessible to individuals who meet the criteria for palliative care and require specialised support that cannot (or difficultly) provided at home. Access to hospice services is not limited to a specific group of people but is based on the individual's clinical needs. The most common ways people can access a hospice service in the UK are[164, 172]:

- Referral by healthcare professionals: General practitioners (GPs), hospital doctors, community nurses, or specialist palliative care teams can make referrals to a hospice services based on their assessment of the individual's needs.
- Self-referral: In some cases, individuals and their families can directly contact a hospice to inquire about their services and request admission. The hospice staff will assess the individual's needs and determine if their services are appropriate.
- Social care referrals: Social workers or local authorities may refer individuals to a palliative hospice if they require end-of-life care and support that cannot be adequately provided in their current setting, such as at home or in a nursing home.

A 2015 study of all decedents who were referred to a hospice-linked MS service shows a significant variation in hospice size, with one hospice receiving 171 patients in a year while another receives 4255.[152]

Access is greater in the UK for those living in urban areas, with closer proximity to a hospice and/or to associated services (e.g. day centres, home care).[46]

Figure 4 – Geographical repartition of hospices across the United Kingdom, 2019



Source: Figure retrieved from Chukwusa et al., 2019[173]

Within England, there was a marked difference in referral to death between hospices in the North of England (35 days) compared with hospices in the Midlands (55 days), London (49 days) and South of England (55 days). And through UK, the difference is even more marked with a median number of days from referral to death ranging from 56 days in Scotland to 17 days in Wales.[152]

Staffing is also a factor influencing the timing to be referred to hospices. Hospices with 4–5 FTE doctors was associated with an 18% increase in referral to death days compared to decedents from hospices with 0–3 FTE doctors.[152]

The NICE guideline on specialised PC services includes recommendations on providing out-of-hours care.[150] Adults approaching the end of their life, their informal caregivers and other people important to them should have access to a healthcare professional (available 24 hours a day, 7 days a week) who can access the person's records and advance care plan, and make informed decisions about changes to care. They also should have access to an out-of-hours end of life care advice line and to an out-of-hours pharmacy service that has access to medicines for symptom management.[150] Profile of patients admitted in hospice in- and out-patient services.

UK hospices offer service to predominantly adult patients with cancer, with more than half of all referrals occurring in the last 7 weeks of life (median time 48 days) and 40% occurring within 30 days of death.[152] There is few difference between woman and men to be referred to hospice early (>30d) or late (< or=30d). Compared to males, the number of day between referral to death was 4% greater for women. However, significant differences were found across age groups, with fewer days between referral and death as age increases. Compared to adults aged <50 years, adults aged 50–74 years had 7% fewer days of hospice-based palliative care. This relationship was amplified for adults aged 75 years and over who had 18% fewer days of hospice-based palliative care compared to adults aged <50 years.[152] Evidence of 2019 suggests that the oldest old (aged 85+) are also under-represented, alongside considerable disparities across geographical regions of the UK.[46]

In 2019 hospices were the place of death for 1.2% (4,503) of non-cancer deaths in UK and 16.5% (24,925) of cancer deaths. Of the 29 428 deaths in hospices in 2019, 24 925 (84.7%) were from cancer and 4503 (15.3%) from non-cancer.[46] The proportion of non-cancer deaths and haematological malignancy occurring in hospice in England and Wales has increased over the past decade, from 7.8% in 2010 to 12.4% in 2015 and 15.3% in 2019.[46]

Early referral is good for patients with breast cancer (median 81 days), patients with neuro-degenerative disease like motor neurone disease (109 days) or patients with heart failure (median 67 days). However, patients with stroke or dementia are referred the last (median 9 days).[152] And patients with liver failure, kidney failure, non-cancer lung disease, liver cancer or rare cancer are more likely to be referred to hospice later.

5.3.4 Staffing and training

Staffing of hospices depends on the financial means of the institution. Nursing care and medical support is always available. Other professionals are also involved if possible.[158, 174, 175]

- nurses (specialised)
- medical doctors (GPs or specialists, e.g. psychiatrists)
- care assistants
- physiotherapists (e.g., rehabilitation therapy, prevention of falls)[176]
- Occupational therapists[177]
- Social informal caregivers (workers): information about coping financially[178]
- Psychologists
- Dietitians,
- Speech therapist
- Counsellors (music therapists, art therapists)
- spiritual and psychological help

- informal informal caregivers and family members
- Respite informal caregivers (looking after the palliative patient so their informal informal caregivers can have a break from caring for a short while

In 2022-2023, 16 000 clinical and care staff were employed by hospices in the UK. Of these, 12 200 are nurses and healthcare assistants and 950 are doctors. Some doctors are employed by NHS hospitals and/or health and social care boards to work across hospitals and hospices.[179]

In the UK, about 160.000 volunteers give around 23 million hours of time every year. Besides voluntary sector hospices, volunteers are also involved (to a smaller extent) in NHS funded hospices. The role of volunteers changes depending on the stage of development of the hospice. In the founding stages, volunteers within the local community drive the idea forward. Once paid staff are employed the role changes to a more supporting role (except the hospice board where volunteers remain to have the lead).[156]

Volunteers in the UK have three roles in hospice services: direct support, organisational support, and income generation and awareness raising. The first is the role in direct care to patients and their families, and includes practical (housework, shopping), social (taking patients out, spending time with patients), and emotional support (bereavement support, talking about end-of-life, spiritual care). Organisational practical support includes reception work, administrative support, helping in housekeeping, serving meals, and maintenance of the building. Finally, income generation and awareness raising included supporting (or organizing) activities intended to generate income (such as giving talks, organizing events, undertaking collections, and writing thank letters).[156]

Success factors for palliative hospice volunteering are, among others, sufficient training in working effectively with volunteers, staff acceptance, description of roles and boundaries, effective recruitment, support and supervision of staff, integration of volunteers and professional staff, clear structures and policies, valuing and empowerment of volunteers, shared leadership, flexibility, mentoring, and strong partnerships with local players.[156]

Quality and safety in hospice volunteering are important. There are no national standards, but a lot of organisations have successfully achieved the national quality generic standard Investing in Volunteers. All hospice volunteers in the UK undertake training but the content and the intensity of the training depends on the local service. However, certain topic are touched by almost every initiative (e.g., needs of patients and families, understanding death and dying, bereavement, responsibilities and boundaries).[156]

Several professional organisations in the UK (some very regional) are involved in palliative hospice care, working to promote standards of practice, education, research, and support for healthcare professionals and patients. The key umbrella organisations in the field are:

- Hospice UK: Hospice UK is the national charity for hospice and palliative care in the UK. They provide support and guidance to hospices across the country, promote the delivery of high-quality care, and advocate for the needs of individuals with life-limiting illnesses. Hospice UK offers various resources, training, and networking opportunities for professionals working in the field.[180]
- Association for Palliative Medicine of Great Britain and Ireland: It is a professional membership organisation for healthcare professionals involved in palliative medicine. Their members include doctors, nurses, and other healthcare professionals working in palliative care settings. It aims to promote and advance education, research, and standards of practice in palliative medicine.[181]
- National Council for Palliative Care: It is an umbrella organisation that brings together individuals and organisations involved in palliative and end-of-life care. They work to improve the quality of care, advocate for policy changes, and raise awareness about the importance of palliative care. It provides resources, information, and support to professionals, patients, and families.[182]
- Marie Curie: Marie Curie is a leading charity in the UK that provides care and support to individuals with terminal illnesses, including palliative care services. They work in partnership with the NHS and other organisations to deliver high-quality care and support for patients

and families. Marie Curie also conducts research and advocates for better access to palliative care.[183]

Palliative and hospice care professionals undergo specialised training and education to ensure they have the necessary knowledge and skills to deliver high-quality care. Professional organisations and hospice professionals offer training programs, conferences, and workshops to support ongoing professional development and ensure staff members are up to date with best practices.

5.3.5 Quality of care in hospice services and in general

In the UK, striving for quality of care in palliative hospices involves a combination of regulatory bodies, standards, assessments, and monitoring processes. Hospices must comply with relevant regulations and standards governing healthcare in the UK. This includes adherence to legal requirements, health and safety standards, and protocols related to infection control.

The Care Quality Commission (CQC) is the primary regulatory body for health and social care services in England. It assesses and monitors the quality and safety of care provided by hospitals, hospices, care homes, and other healthcare professionals. In Wales, the Healthcare Inspectorate Wales oversees the quality and safety of healthcare services, including palliative care. It ensures that healthcare professionals in Wales meet established standards. The Health Improvement Scotland is responsible for the regulation and improvement of healthcare services in Scotland. It may be involved in overseeing palliative care services to ensure they meet quality standards. In Northern Ireland, the Regulation and Quality Improvement Authority regulates and inspects the quality and safety of health and social care services, including those related to palliative care.

Hospices are subject to regular inspections by the CQC to assess and monitor the quality and safety of care provided. Hospices are expected to meet the CQC's Fundamental Standards, which cover areas such as person-centred care, safety, effectiveness, responsiveness, and leadership.[184] Hospices must demonstrate compliance with these standards and take necessary actions to address any areas of non-compliance identified during inspections.[167] The inspection process includes a review of policies, procedures, patient records, and direct observations of care delivery. The CQC evaluates hospices based on five key areas: safety, effectiveness, caring, responsiveness, and well-led. Ratings are provided for each of these areas, and an overall rating is assigned to the hospice. Hospices are rated by the CQC, and their reports are publicly available, enabling transparency and accountability.[145] They provide reports with the results of their assessments (e.g. The state of hospice services in England 2014 to 2017).[185]

Various organisations, such as Hospice UK and the Association for Palliative Medicine of Great Britain and Ireland, have developed quality standards and guidelines for palliative and hospice care. These standards define the expected level of care and cover areas such as symptom management, communication, psychological support, and end-of-life care planning. Hospices are encouraged to align their practices with these standards.[174] Palliative hospices typically have their own internal quality assurance processes to monitor and control the quality of care. This can include regular reviews of care practices, audits, and feedback mechanisms from patients, families, and staff. By monitoring their own performance and outcomes, hospices can identify areas for improvement and take appropriate actions.[171]

Palliative hospices often engage in peer review and collaboration to exchange knowledge, share best practices, and learn from each other. This can involve participating in regional or national networks, quality improvement projects, and research initiatives. Collaborative approaches promote shared learning and continuous quality improvement across hospice settings.[186] Gathering feedback from patients and their families is a crucial component of evaluating the quality of care. Many hospices actively seek input through surveys, interviews, or feedback sessions to assess patient satisfaction and identify areas for improvement. However, this is not mandatory. But typically, hospices have clinical governance structures in place to ensure ongoing monitoring and improvement of care quality. This includes internal audits, risk management processes, and learning from incidents. Monitoring performance indicators and outcome measures helps hospices assess the impact of their interventions on patient well-being. This

may involve tracking symptom management, patient satisfaction, and other relevant metrics.

5.3.6 Referrals, multidisciplinary consultation, data sharing and integrated care

Hospice care professionals work closely with other health and social care professionals providing palliative and end of life care in the community, including GPs, social care staff and district nurses.[46] Palliative and hospice care is typically provided by a multi-disciplinary team consisting of healthcare professionals with different specialties. This team approach ensures that individuals receive comprehensive and coordinated care. The team may include doctors, nurses, social workers, counsellors, chaplains, and other healthcare professionals, each contributing their expertise to provide holistic care.[187] They often have multidisciplinary consultations to discuss individual patient care (following a NHS guiding book).

Studies led by the Marie Curie charity on the "*Choice in End-of-Life Care Programme*" have highlighted the benefits of taking a whole systems approach to the delivery of end-of-life care. Further work on the cost impact of new end of life care service models, developed through the "Marie Curie Delivering Choice Programme", is encouraging, showing a reduction in hospital admissions and increase in home deaths with stable overall costs.[142, 143]

The NICE guideline NG142 includes recommendations on communication between services, the provision of multipractitioner care, the care coordination and on transferring people between care settings.[150]

5.4 France

5.4.1 Whole context of palliative care services

In 1979, France surfed the waves of the British development of palliative hospices (Dame Cisely Saunders - see above) by establishing the first French palliative care unit at the Gustave Roussy Cancer Institute in Villejuif, near Paris.[188, 189] This unit focused on providing specialised care for cancer patients at the end of life. The development of palliative care gained momentum in France during the 1980s, notably with the creation of the palliative care unit at the international hospital of *Cité Universitaire*.[190] Then several institutions started offering palliative care services. The French National Cancer Institute (INCa)[191] played a significant role in promoting and supporting the development of palliative care across the country.

In the 1990s, the French government recognized the importance of palliative care and took steps to promote its integration into the healthcare system. In 1993, the French Ministry of Health launched a national program to develop palliative care services, focusing on training healthcare professionals, improving access to pain management, and establishing specialised palliative care units. The 2000s witnessed further progress in the development of palliative care in France. The French National Cancer Plan, launched in 2003, included palliative care as a priority area, aiming to ensure that all cancer patients have access to high-quality palliative care services.[192] The plan emphasized the need for multidisciplinary care teams and the integration of palliative care into all healthcare settings.

The development of palliative care in France has been influenced by several key legislations. Three legislations, among others, have provided a legal framework for the development and provision of palliative care services in France.[193] They have emphasized the importance of pain management, symptom relief, patient autonomy, and respect for patients' dignity and wishes at the end of life. Those significant legislations are:

- Law 2002-303 (2002) - Law on Patients' Rights and the Quality of the Health System (*Loi n° 2002-303 du 4 mars 2002 relative aux droits des malades et à la qualité du système de santé*)[194]: this law reinforced the rights of patients, including those with life-limiting illnesses, to receive

quality healthcare. It emphasized the need for healthcare professionals to ensure pain relief and support for patients and their families.

- Law 2005-370 (2005) - Law on Patients' Rights at the End of Life and the Development of Palliative Care (*Loi n° 2005-370 du 22 avril 2005 relative aux droits des malades et à la fin de vie*)[195]: this law, commonly known as the "Leonetti Law," addressed end-of-life care and the development of palliative care services. It established the right of patients to receive appropriate treatment to alleviate pain and suffering. The law emphasized the importance of advance directives and the role of healthcare professionals in respecting patients' wishes regarding medical treatments and end-of-life decisions.
- Law 2016-87 (2016) – Law creating new rights for the sick and people at the end of life (*Loi n° 2016-87 du 2 février 2016 créant de nouveaux droits en faveur des malades et des personnes en fin de vie*[196]: this law, also known as the "Leonetti-Claeys Law," expands upon the provisions of the Leonetti Law. It further clarifies the rights of patients at the end of life, including their access to palliative care, the right to continuous deep sedation, and the right to refuse medical treatment. The law also introduces the concept of "advance chronic disease directives" to allow patients to express their wishes regarding medical care and treatment options in the context of chronic diseases. The 2016 law reinforces the value of advance directives that have existed since the 2002 law.[197]

The implementation of legislations has been accompanied by national plans to structure and support the development of palliative care, in particular by supporting the establishment of multidisciplinary structures and teams working in health establishments or at home.[198, 199]

- Three-year Palliative Care Development Plan (1999-2001)
- National Palliative Care Development Program (2002-2005)
- National Palliative Care Development Program (2008-2012)
- Plan for the development of palliative care and end-of-life support (2015-2018)
- National Plan “Development of palliative care and end-of-life support” (2021-2024)

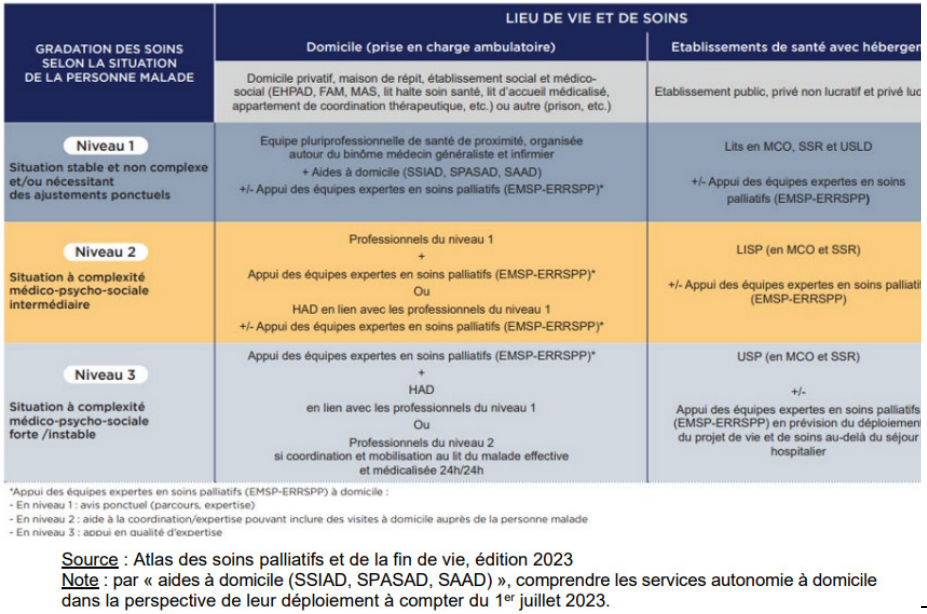
Building on the momentum of the previous four national plans, the fifth plan 2021-2024 reflects the commitment to guarantee access to graduated, appropriate and local palliative care for all citizens, throughout the country and in all areas of life. This plan aims to improve information for people, to increase the supply of palliative care both in the community and in institutions, to program treatments earlier in the healthcare pathway, to strengthen training in palliative care, and to promote expertise by funding research work and thus improving knowledge in this field.[200] The global outcome is to structure the sector in such a way as to guarantee patients and their families graduated palliative care, coordinated with the front line, and to provide professionals - particularly nursing home teams - with the necessary support and expertise in palliative care and end-of-life support. One hundred seventy one million euros have been allocated by the government, including 5 million euros to strengthen mobile teams.[201]

Graduated PC is defined in the Atlas 2023.[200] Graduated care is the result of a gradation of the needs of patients and their families in terms of palliative care. It requires the Regional Health Agencies (*Agences regionals de santé – ARS*), which are regional branches of the French Ministry of Health that oversee healthcare provision in their respective regions, to structure palliative care provision, support for care professionals and the coordination of stakeholders according to a gradation of care, within care networks, which is organised according to the place of care (in an institution or at home) and according to the choices of the person, taking into account the level of complexity of the situation, the intensity of care required and the stakeholders who can be mobilised. There are three levels of care.[198, 199]:

- Level 1 corresponds to stable, non-complex situations and/or situations requiring occasional adjustments.
- Level 2 corresponds to situations of intermediate medico-psycho-social complexity.
- Level 3 corresponds to situations of high or unstable medical, psychological, and social complexity.

Figure 5 summarises the graded palliative care services available, depending on the patient's state of health, at home and in hospital.

Figure 5 – Graded palliative care services in France



GRADATION DES SOINS SELON LA SITUATION DE LA PERSONNE MALADE	LIEU DE VIE ET DE SOINS	
	Domicile (prise en charge ambulatoire)	Etablissements de santé avec héberger
	Domicile privatif, maison de répit, établissement social et médico-social (EHPAD, FAM, MAS, lit halte soin santé, lit d'accueil médicalisé, appartement de coordination thérapeutique, etc.) ou autre (prison, etc.)	Etablissement public, privé non lucratif et privé luc
Niveau 1 Situation stable et non complexe et/ou nécessitant des ajustements ponctuels	Equipe pluriprofessionnelle de santé de proximité, organisée autour du binôme médecin généraliste et infirmier + Aides à domicile (SSIAD, SPASAD, SAAD) +/- Appui des équipes expertes en soins palliatifs (EMSP-ERRSPP)*	Lits en MCO, SSR et USLD +/- Appui des équipes expertes en soins palliatifs (EMSP-ERRSPP)
Niveau 2 Situation à complexité médico-psycho-sociale intermédiaire	Professionnels du niveau 1 + Appui des équipes expertes en soins palliatifs (EMSP-ERRSPP)* Ou HAD en lien avec les professionnels du niveau 1 +/- Appui des équipes expertes en soins palliatifs (EMSP-ERRSPP)*	LISP (en MCO et SSR) +/- Appui des équipes expertes en soins palliati (EMSP-ERRSPP)
Niveau 3 Situation à complexité médico-psycho-sociale forte /instable	Appui des équipes expertes en soins palliatifs (EMSP-ERRSPP)* + HAD en lien avec les professionnels du niveau 1 Ou Professionnels du niveau 2 si coordination et mobilisation au lit du malade effective et médicalisée 24h/24h	USP (en MCO et SSR) +/- Appui des équipes expertes en soins palliatifs (EMSP-ERRSPP) en prévision du déploiement du projet de vie et de soins au-delà du séjour hospitalier

*Appui des équipes expertes en soins palliatifs (EMSP-ERRSPP) à domicile :
- En niveau 1 : avis ponctuel (parcours, expertise)
- En niveau 2 : aide à la coordination/expertise pouvant inclure des visites à domicile auprès de la personne malade
- En niveau 3 : appui en qualité d'expertise

Source : Atlas des soins palliatifs et de la fin de vie, édition 2023
Note : par « aides à domicile (SSIAD, SPASAD, SAAD) », comprendre les services autonomie à domicile dans la perspective de leur déploiement à compter du 1er juillet 2023.

Source: Figure retrieved from the Circulaire DGOS/R4/DGS/DGCS/2023/71 of 21 June 2023, page 7[199]

At the present time (and before the implementation of the future strategy 2024-2034), France has already a well-established offer of palliative care services: the generalist one and the specialised one. Circular DHOS/O2/2008/99 of 25 March 2008 on the organisation of palliative care set out the framework for graduated specialised palliative care provision and provided guidelines for each of the specialist palliative care services identified at that time[202]: (i) Palliative care units (*unités de soins palliatifs - USP*), (ii) Palliative care outreach teams (*équipes mobiles de soins palliatifs - EMSP*), (iii) Regional paediatric palliative care resource teams (*équipes ressources régionales de soins palliatifs pédiatriques - ERRSPP*)[i], (iv) Identified palliative care beds (*lits identifiés de soins palliatifs – LISP*), (v) Hospital at home (*Hospitalisation à domicile-HAD*).

Here under a description of each type of specialised palliative care services[193, 203]:

- A Palliative Care Unit (PCU) is a service whose beds are entirely dedicated to palliative care and support at the end of life. It is both a place of care and a place of life for patients and their families. The PCU provides temporary or permanent care for people suffering from serious, progressive, life-threatening, advanced or terminal illnesses, when care requires the intervention of a multidisciplinary team with specific skills, or when patients can no longer be cared for at home, in a medico-social establishment, or in their original hospital department. The PCU has a triple mission of care, research and training for informal caregivers.[200] In 2019 there were 164 PCUs in France.[204] PCU can be located in a hospital or as stand alone facility.
    - Hospital-Based PCUs are typically located within larger general hospitals and offer comprehensive care. Hospital-based palliative care units collaborate closely with other hospital departments to ensure coordinated care. Hospital-Based PCUs take care for complex palliative cases. They may have a homelike environment, offering a comfortable and supportive setting for patients and their families. They often have specialised rooms/subunits for symptom management, end-of-life care, and family support. Patients in palliative care units generally have shorter stays, usually during the end-of-life phase. The goal is to provide specialised care and support in the final weeks or months of life.[205]

[i] This type of service is out of scope for this report.



- Independent PCUs are standalone facilities dedicated to providing specialised palliative care. These freestanding PCUs are quite rare in France. They are designed to create a home-like environment, focusing on comfort, support, and quality of life for patients nearing the end of life. These services often have interdisciplinary care teams and offer a range of services, including medical care, pain management, psychological support, and family counseling. They do not seem to be recognized by French policy (e.g., Maison Médicale Jeanne Garnier in Paris[j]). In fact these structures are considered palliative care units and not as hospice services.[190]

- Identified palliative care beds offer specialised palliative care in a hospital ward that is frequently confronted with end-of-life situations, but whose activity is not exclusively devoted to palliative care. The individualisation of identified palliative care beds within a department makes it possible to provide appropriate palliative care thanks to a specific organisation and the reinforcement of the palliative care skills of the medical and paramedical teams. Medical and supportive care is generally provided by the same teams that took care of the initial illness. They provide an intermediate level of care.[200] In 2019, there were 901 organisations with identified PC beds in France.[204]

- Palliative Care Outreach Teams is usually named 'mobile palliative care teams'. It is made up of doctors, nurses, psychologists and social workers whose role is not primarily to provide care but to support and provide expertise to the care teams and professionals who call on them. They visit patients and provide specialised palliative care advices and support in the preferred setting of the patient.[202] They work in hospitals, social and medico-social establishments (nursing homes, etc.) and at home. It may be attached to a health establishment or to a territorial coordination structure. Mobile teams work closely with the patient's primary healthcare provider and specialists to ensure coordinated and integrated care. They collaborate with hospitals, hospices, and other healthcare facilities to facilitate seamless transitions and continuity of care. The mobile PC team can be requested by patients, their families or informal caregivers, and intervenes in different care and living environments. As part of its remit, the mobile team helps to raise awareness among professionals and train anyone involved in palliative care and end-of-life support.[200] In 2019, 427 mobile teams were active in France. From this, 22 focused on pediatric care (out of scope for this report).[199]

- Palliative hospitalisation at home is part of the national healthcare system in France. Hospital at home (HAH) is full-time hospitalisation during which care is provided in the patient's own home (at home or in a social or medico-social establishment like nursing homes or establishments for people with disability or for homeless people). HAH has the necessary skills to provide palliative care at home. Otherwise it relies on a mobile PC team. HAH are requested when the patient requires complex medical, psychological and social care, specific technical skills, particular medical instability or when the care load is high. As it ensures that the patient's regular care team remains, it operates in addition to home nursing care. To receive palliative hospitalization at home, patients must have a life-limiting illness and meet certain criteria established by the healthcare system. HAH services devote 40% of their activity to palliative care.[190]

In addition to these specialised PC services, hospital can also sometimes provide palliative day hospital ("*Unités de Soins Palliatifs de Jour*" or simply "USP de Jour.") designed to provide a range of specialised PC interventions and support to patients with life-limiting illnesses who do not require 24-hour inpatient care.

Otherwise, like in other countries, many palliative situations are handled by generalist PC services[193, 203]:

[j] More information (in French): https://www.jeanne-garnier.org/le-sejour/maison-medicale-jeanne-garnier/

- Generalist palliative care at home is carried out by family doctors, nurses and home help services including nursing assistants and professionals responsible for housekeeping. The decision to provide home care is based on the patient's medical condition, their preference, and the availability of resources. Although an increasing number of doctors and nurses working in home care have quite advanced training in palliative care, they can always call on mobile palliative care teams to help them. [190]
- Long-term care units (*Unité de soins de longue durée; USLD*) offer long term care including generalist palliative care to patients who are quite stable and do not have too complex PC needs. Long-term care units (LTCUs) are included in general hospitals. It is intended for patients who require ongoing medical care and monitoring but do not necessarily have a terminal illness. The focus is on medical management, rehabilitation, and prolonged hospital-based care for patients with chronic conditions or complex medical needs. LTCUs are reserved for people aged over 60 and seventy-seven percent of the admitted patients were older than 75 years.[200] The setting is comparable to a traditional hospital environment. The duration of stay can vary depending on the patient's condition and needs, but it typically involves months or even years of hospital-based care.[205] In 2019, 19 800 patients were admitted to LTCUs.[200] On the other hand, France has also numerous follow-up care and rehabilitation services (medium stays) which welcome many patients requiring generalist palliative care for stays of 1 to 3 months.[190]
- Nursing homes: in France distinction is made between *Etablissement d'hébergement pour personnes âgées* (*EHPA*) and *Etablissement d'hébergement pour personnes âgées dépendantes* (*EHPAD*). Especially the *EHPAD* can take up the role of residential palliative care provider.[200]

The different services composing the PC offer in France and the guidelines describing it should be updated to meet current needs. Spontaneous and progressive transitions already occurred since 2008. For example, palliative care consultation services are cited by one author.[206] and palliative care units and mobile teams, initially intra-hospital, had shifted gradually to intra- and extra-hospital.[190] The new 2024-2034 strategy takes partially account of this need for specialised PC services renewal. New guidelines for PCU, identified PC beds, HAH, day hospital (*hôpital de jour – HDJ*), and mobile teams are proposed in the appendices to the 2023 interministerial instruction of 21 June 2023 (N° DGOS/R4/DGS/DGCS/2023/76) preparing the 10 years strategy 2024-2034.[199] In addition, to fulfil the principles described in this interministerial instruction and to match with the graduated offer set up in the Atlas of PC and end of life in France, edition 2023[200], authorities plan to develop the territorial and regional networks in the future as followed:

- a graduated offer of help and care, allowing the identification of palliative situations, the initiation of palliative care in proximity around the attending physician or a referral team at home. Home includes personal residence and all places of reception and accommodation.
- hospitalization accessible to all three levels of recourse (including identified beds of palliative care, palliative care units, home hospitalization, etc.)
- home care on the three levels of recourse, mobilizing resources if necessary at supra-territorial level
- the identification and availability of mobile palliative care teams covering all living and care places, including precariousness and disability. Depending on the territory, one or more mobile teams can carry out these missions;
- access to specialist palliative care consultations
- access to a day hospital;
- access to pediatric expertise in palliative care;
- organisation of specialised professionals on duty during the day and extended at the evening, with a regional telephone support service for palliative care 7/7 days - 24/24h;
- organisation of multidisciplinary consultation meetings;
- organisation for the management of palliative emergencies in coordination with the emergency sector;

- facilitated access to volunteers trained in palliative care support;
- access to help and support from informal and professional caregivers;
- access to a bereavement support for the relatives of the deceased;
- training for professionals and staff (both caregivers and non-caregivers);

Palliative care can be delivered in various settings based on the patient's needs and preferences. These settings include hospitals, PC stand-alone facilities, the patient's own home and all living and care facilities including health establishments, private residence places, social and medical-social institutions and services including residential homes for dependent elderly people, temporary reception and accommodation facilities such as health care holding beds, nursing beds, therapeutic coordination apartments, nursing homes, specialised nursing homes, correctional institutions, and accommodation for people in a situation of precariousness.

Hospice services are not mentioned in policy papers and are not listed as recognised PC services by ARS in the French Atlas 2023 of PC.[200] Moreover, the term 'hospice' is used very sparse in France as it has a different connotation, related to poverty and low socio-economic situations. The identification of private initiatives like hospice services is as such very difficult. A national expert explains that, at present, there are no hospice except some sparse private initiatives in France.[190] According to that expert, it is possible that the future PC offer in France would include the creation of '*support homes*' closer to the hospice model with an essential vocation of standard care and support in order to leave specialised structures an important role when medicalization is necessary.[190] According to this explanation, hypothetical '*support homes*' would rather be related to generalist PC service than specialised PC service. However, initiatives of in and outpatient hospice services were identified during the research. One of these initiatives matches with other examples of palliative middle care offer/hospice care services explored in this chapter, this initiative will so be further described in sections 5.4.2. and further.

There are several umbrella organisations in France that are related to and play a significant role in advancing and promoting palliative care. These organisations work to provide guidance, support, and coordination within the field of palliative care. The following key umbrella organisations were identified[207]:

- SFAP (*Société Française d'Accompagnement et de Soins Palliatifs*) - French Society for Palliative Care: professional association that brings together healthcare professionals, researchers, and other stakeholders involved in palliative care. SFAP aims to promote and develop palliative care practices in France through education, research, advocacy, and the dissemination of best practices.[208]
- UNASP (*Union Nationale pour l'Accompagnement en Soins Palliatifs* - National Union for Palliative Care Accompaniment): organisation that brings together volunteers involved in palliative care across various settings, including hospices, hospitals, and home care. UNASP aims to promote volunteer involvement in palliative care, provide training and support for volunteers, and contribute to the humanization of end-of-life care. the national society of palliative care (SFAP) represents more than 6000 volunteers.

Palliative care services in France are financed through a combination of sources, including mainly public funding and sometimes private donations.[199, 209-211] Palliative care services in France receive public funding from the French National Health Insurance (*Assurance Maladie*), a part of the national healthcare system, which is primarily funded through social security contributions. The French government allocates funds to support the provision of palliative care services as part of the broader healthcare system. First the *Assurance Maladie* provides coverage for medical expenses necessary for the patient's comfort and well-being: palliative care services receive reimbursement for the interventions provided to patients through the fee-for-service reimbursement system. This system involves healthcare professionals submitting claims for the care they deliver, and the *Assurance Maladie* reimburses the approved costs based on predetermined rates and fee schedules. Public and private health insurance also covers the costs of nursing care, medication, medical procedures, and laboratory tests. Certain paramedical interventions provided in palliative care services may

also be covered by health insurance. This can include services such as physiotherapy, occupational therapy, speech therapy, and psychological support. In addition, palliative care services receive *per diem* (daily) reimbursement rates for each patient under their care. These rates cover the costs associated with accommodation (the room or bed charges), meals, nursing care, medication, and the costs of medical equipment necessary for the palliative care of the patient such as mobility aids, medical beds, oxygen therapy equipment, and other medical devices as prescribed by the healthcare professionals.

Charitable organisations, foundations and philanthropic individuals[212] may also support financially palliative care services. These entities may contribute funds to cover specific projects, capital investments, or operational expenses of in and outpatient services. Palliative care services in France may also receive financial support from local or regional authorities. These authorities may allocate funds to support the operations and development of palliative care in their respective jurisdictions. This funding can help cover costs such as facility maintenance, equipment upgrades, and specialised training for staff. There may still be co-payments or out-of-pocket expenses for patients, depending on their specific insurance coverage and any additional supplementary insurance they may have.[213]

It's worth noting that the specific financing arrangements and contributions can vary between different PC services in France. Some institutions may rely more heavily on public funding, while others may have a greater dependency on charitable donations and local contributions. Additionally, organisations may engage in fundraising activities, events, and campaigns to supplement their financial resources.[212] However, most funding comes from the state. Private funding is more anecdotal and concerns more equipment.[190]

Access to palliative care in France typically involves a collaborative process between healthcare professionals, patients, and their families. The steps to access PC services might depend on the type of service and the region or geographical distribution.[204, 214] Palliative care services are often accessed through referrals from healthcare professionals involved in the care of the patient. This can include general practitioners, oncologists, palliative care specialists, hospital-based teams, or home care teams. These healthcare professionals assess the patient's condition, prognosis, preferences, and care needs to determine if a referral to a specialised palliative care service is appropriate. Once a referral is made, a comprehensive assessment is conducted to evaluate the patient's needs and determine the most suitable care setting. This assessment typically involves a multidisciplinary team, including doctors, nurses, social workers, and other professionals. The team assesses the physical, psychological, social, and spiritual aspects of the patient's condition to develop an individualized care plan. Based on the assessment, the palliative care team collaborates with the patient, their family, and the available resources to determine the most appropriate care setting. Factors considered include the patient's preferences, symptom management needs, availability of family support, and the capacity of the PC service. If the choice is made, the team coordinates the admission, ensuring a smooth transition and continuity of care.

Palliative care institutions often have a limited number of beds, and availability can vary depending on the specific type and its capacity. The placement process considers the availability of beds and prioritizes patients based on their needs and urgency. In some cases, there may be a waiting period before a bed becomes available, and interim care may be provided in other settings, such as hospitals or the patient's home, until a bed becomes available. The geographical distribution of palliative beds (primordially in-hospital beds) in France seems to be suboptimal as 26 counties (*départements*) lack PCU beds.[204]

Statistics show that 60% of the French population die in a healthcare institution (less than 3% of these dies in a palliative care unit), 10% die in a nursing home and less than 30% dies at home (from which about 2% benefit from palliative hospital at home service).[215] Amongst the palliative population, 19% dies at home, 56% dies in a hospital, 22.5% dies in nursing home and 2.5 dies elsewhere (including hospice initiatives).[216] For people with cancer specifically, 88% received palliative care during stays in hospital acute care units, 17% in rehabilitation units and 15% in hospital-at-home services.[217]

The types of patients who enter palliative care can vary in France but a significant proportion of patients have cancer.[200] Palliative care for cancer patients aims to alleviate pain, manage symptoms such as nausea or

shortness of breath, and provide emotional and psychological support. Palliative care services also support care to individuals with non-cancer life-limiting conditions, such as advanced heart disease, neurological disorders, respiratory diseases, or end-stage organ failure. These patients may have complex care needs and require specialised support to enhance their comfort and well-being. Finally, palliative care services may admit patients with progressive degenerative diseases such as Alzheimer's disease, Parkinson's disease, or amyotrophic lateral sclerosis. These patients may require palliative care as their conditions advance, focusing on managing symptoms, maintaining comfort, and providing emotional support to both patients and their families.

Palliative care services in France typically have a multidisciplinary team of healthcare professionals who collaborate to provide comprehensive care to patients.[218] Their professional background is similar to the other countries already described: 1) Doctors; 2) Nurses; 3) Social Workers; 4) Psychologists; 5) Spiritual Counsellors; 6) Pharmacists; 7) Rehabilitation Therapists; 8) Dietitians/nutritionists; 9) Speech therapists; 10) Palliative care coordinators

Initial and continuing training for doctors, pharmacists, nurses, care assistants, home informal caregivers and clinical psychologists includes teaching on palliative care.(Law 2016-87 (2016) – Law creating new rights for the sick and people at the end of life (*Loi n° 2016-87 du 2 février 2016 créant de nouveaux droits en faveur des malades et des personnes en fin de vie*[196]:

Also volunteers play quite an important role in palliative care in France. While healthcare professionals provide the necessary medical treatments, volunteers offer additional assistance, companionship, and emotional support. In France, volunteers in palliative care are commonly referred to as 'accompaniment volunteers' (*bénévoles d'accompagnement*).[189] They work closely with healthcare professionals, such as doctors and nurses within specialised palliative care services, hospices, or home care settings. Their primary roles are: (i) companionship and emotional support for patients and families, (ii) practical assistance (e.g., light housekeeping, meal preparation, offering respite to families), (iii) recreational activities, (iv) end-of-life support (e.g., sit vigil with patients, offer comfort measures, help create a calm and peaceful environment), (v) bereavement support (emotional support, participate in group talks).

These volunteers are typically trained, coordinated and supervised by healthcare organisations or nonprofit associations specialised in palliative care to ensure that volunteers can effectively contribute to the well-being of patients and their families. They undergo training programs to develop the necessary skills and knowledge for their roles. These training programs typically cover topics such as active listening, communication skills, understanding the emotional aspects of end-of-life care, and maintaining professional boundaries.[219]

In France, the legal framework for volunteering is governed by the French Civil Code (*Code civil*) and various laws and regulations. While there is no specific law dedicated solely to volunteers in palliative care, the general principles of volunteering and its application to palliative care are outlined in relevant legislation.

Palliative care services in France are subject to regulatory oversight by government agencies, such as the Ministry of Health and regional health authorities (*Agences Régionales de Santé* - Regional Health Agencies ARS). These authorities establish and enforce regulations and standards that these must adhere to, including requirements related to staffing, infrastructure, safety, and quality of care. Palliative care services undergo a certification process to demonstrate their compliance with the quality standards. The certification is conducted by independent organisations, such as the *Haute Autorité de Santé* (*HAS*)[220] or the *Agence Nationale de l'Évaluation et de la Qualité des Établissements et Services Sociaux et Médico-sociaux* (*ANESM*).[221] Certification is renewed periodically, ensuring ongoing compliance with quality criteria. Also, the Regional Health Agencies (ARS) play a role in evaluating palliative care and ensuring compliance with regulations and standards. Various quality indicators and performance measures are used to monitor and assess the quality of care in palliative care. These indicators can include measures related to pain management, symptom control, patient, and family satisfaction, support psychosocial support, and end-of-life communication. The data collected through these indicators helps identify areas of strength and areas that require improvement. Also gathering feedback from patients and their families is an

essential part of evaluating the quality of care in palliative care in France. Feedback can be collected through surveys, interviews, or focus groups to assess their experiences, satisfaction levels, and perceptions of the care received. This feedback provides valuable insights into the strengths and areas for improvement in care delivery. Finally, independent reviews and audits may be conducted by external organisations or regulatory bodies to assess the quality of care in palliative care facilities. These reviews can involve site visits, interviews with staff and patients, and assessments of documentation and processes. The findings of these reviews contribute to the evaluation of the performance of palliative care initiatives and identify opportunities for enhancing care.

France has established a nationwide network of palliative care services (*réseaux de soins palliatifs*). These are regional or territorial networks that coordinate and improve the provision of palliative care services in each area. They facilitate collaboration and communication among various healthcare professionals, including hospitals, home care services, and community facilities, to ensure continuity and quality of care for patients in different settings. The structuring of networks to encourage exchanges between services and professionals is the subject of the 2023 interministerial instruction.[199]

Current French policymakers want to promote the complementary nature of palliative care teams and the possible pooling of their human and logistic resources. They want to develop end-of-life support services through stronger partnerships with voluntary support associations. They also aim to support coordination and collaboration between professionals and those involved through multidisciplinary and collegial reflection. Finally, they will provide time slot for discussion and listening around complex or destabilising situations and set up psychological support for those involved.[199]

Structuring the regional palliative care network will specify the organisation and links between the professionals involved, but also with other existing care networks (geriatrics, oncology, paediatrics, emergencies, cancer, rare diseases, chronic and neuro-evolving diseases, organ failure, etc.). It may take the form of a partnership agreement co-signed by the ARS and those involved in the regional palliative care network.

The network includes all healthcare establishments, including hospital at home, which provide care for people requiring palliative care, particularly those with specialised palliative care activities. It also identifies social and medico-social establishments and services and community healthcare professionals who provide care for people receiving palliative care. The role of each provider is defined in a formal agreement with all the professionals involved in the network, and is based on a set of guidelines.[199]

As the reader can notice, the descritpion of the whole context of PC is extensive for France as the absence of hospice in France prevents to focus the descripion on hospice services. However an illustrative example of a private initiative of hospice service, named "*La Maison*", will be explored through the same items used to describe in and outpatient hospice services elsewhere.[222]

5.4.2 Description of the hospice 'La Maison'

"*La Maison*" is a palliative care facility located in Gardanne, South of France. It was set up in 1994, in the context of the HIV epidemic. It has several services:

- two palliative care units with 12 beds each (24 inpatient beds). Each patient has his own room. The rooms are spacious enough to accommodate an extra bed. In addition, four rooms are available for families. Visiting hours are flexible and children are welcome. Technical care is provided as a priority to treat pain and other symptoms in order to restore the best possible quality of life. Well-being treatments are offered by informal caregivers trained in various techniques: energy resonance through skin stimulation, hypnosis, relaxation, Bach flowers, touch massage and aromatherapy.
- a day centre with a capacity of 5 residents per day from Monday to Friday (25 places per week) for vulnerable people with serious illnesses, where art, culture and creativity are proposed. Professional artists from a variety of disciplines run the day centre on a voluntary basis. Participants are patients and informal caregivers. These workshops recreate social links, providing a place to exchange ideas and listen to what people have to say. Outings are an opportunity to discover

exhibitions and musical, choreography or theatrical experiences. In addition to the artistic programme, relaxation and wellbeing treatments are provided on a voluntary basis by body practitioners.

- a territorial outreach palliative care team. It is part of the territorial PC network organisation: the '*Pôle de Soins Palliatifs (PSP 13)*' which accompanies and supports the care process of patients in the place of their choice throughout the *Bouches-du-Rhône* county. This network includes 5 outreach PC teams. A coordination unit (*RéSP 13*) receives, regulates and directs requests for palliative care to one of the outreach teams. The team delivers a comprehensive approach to each situation through expertise, listening, advice and support. It cooperates with homecare workers.
- a long-term palliative care unit: the Villa Izoï including 14 inpatient beds. This is a home for people suffering from an incurable and progressive illness who find themselves in a phase of their illness that has become chronic, with a real loss of autonomy, slowly and inevitably evolving, and whose social consequences impact on their ability to remain in their own home. This facility is for people under 60 years of age and provides medical care based on the basic needs of patients and their families. Priority is given to patients suffering from cancer, neurological diseases and infectious diseases. It offers an environment adapted to these pathologies and the resulting disabilities. A life project is set up around artistic activities and comfort care. Organised as a place to live rather than a hospital, Villa Izoï is a place of residence where solidarity and caring for others are at the heart of the project.
- a training organisation for healthcare professionals, volunteers and students. Training days are offered to nursing staff in care services (public and private hospitals, clinics, retirement homes, nursing homes, medico-social institutions, home nursing services), to self-employed nurses, to staff of home help associations and to volunteer associations. Our teaching team is made up of instructors with expertise in palliative care, with between 10 and 30 years' experience in the field. The courses are accessible to people with all types of disability.
- a bereavement support of two types: workshops for children experiencing bereavement and discussion groups for families

"*La Maison*" is committed to welcoming, caring for and relieving pain and symptoms, and to supporting each person in their individuality. It works as part of a team and develops the principle of collaboration between everyone and promotes exchanges with the various medical, social, and public partners. It supports and trains 'PC teams' throughout their involvement. It integrates the cultural dimension into care settings and fosters a creative spirit with local artists and associations. It encourages innovation in improving communication and developing palliative culture through culture and research.

5.4.3 Financing of the hospice 'La Maison'

"*La Maison*" is a state-funded, not-for-profit private healthcare establishment of collective interest. It is managed by the '*Association La Maison*', under the law of 1901, which has been recognised as being of public interest since 2011. Donations and subsidies from regional and local authorities, foundations, private associations, private donors, families, etc. are reinvested in innovation and the development of new services.

5.4.4 Access to the hospice 'La Maison' and target population

Anyone suffering from a serious and progressive illness, in a palliative situation, and his/her informal and professional caregivers can be admitted in the PCU of '*La Maison*'. Patients with impaired consciousness, communication disability or mental health problems may be admitted. Highly technical care such as respirators, oxygen therapy, pleural drains, iv pumps, epidurals, morphine pumps and tracheostomy care are also available.

The admission form for '*La Maison*' hospice services include contact details for the patient, relatives, and informal caregivers. It also asks for the main pathology, the history of the illness, any associated pathologies, the therapeutic plan, the treatment, the physical and psychological symptoms, and the social context. A tab is also provided for communicating the level of information provided to the patient, family and contact person concerning the diagnosis, prognosis, and palliative plan. Using this form, applicants can

specify whether they are seeking end-of-life care or a temporary stay for family respite or to treat symptoms. Information about the patient's usual place of residence and a possible return to it is also requested.

The day centre supports people with a serious and progressive illness who live at home, alone, with their family or in a therapeutic flat.

The patient, the patient's family and friends, the patient's GP, the various people working in the home, the referring hospital team, etc. can ask the support of the territorial outreach PC team via the regional coordination centre.

The long-term palliative care unit, the Villa Izoï, accommodates vulnerable patients. It responds to a need identified by those involved in palliative care who are increasingly confronted with the issue of 'long dying'. This innovative service aims to fill the gap in the current healthcare system, concerning those for whom medicine has postponed death for a time, at the cost of a situation of 'long death' and its discomfort. Hospitals are no longer the answer. Palliative and aftercare centres cannot absorb this demand, which is inappropriate for their long-term missions.

5.4.5 Staffing of the hospice 'La Maison'

The composition of the staff at '*La Maison*' follows the principle of multidisciplinary required to provide high-quality specialist palliative care.

The establishment is managed by 6 administrative professionals. Logistical tasks are entrusted to 15 professionals (kitchens, cleaning, repairs). All clinical services can also count on the support of a social worker, a pharmacist and his assistant, and a training manager. Finally, the non-outreach services are supported by a hygiene and medical equipment coordinator and a team of volunteers and their coordinator.

The territorial mobile team is made up of a doctor, a coordinator, a psychologist, three nurses and a secretary. The day centre includes the same profiles in the same numbers as the mobile team, but without the 3 nurses. On the other hand, two medical and psychological assistants, a care assistant, an activity leader, volunteers, and external contributors complete the staff. The long-term palliative care unit has a large and varied team. In addition to a doctor, two coordinators, a psychologist, seven nurses, five care assistants, two medical-psychological assistants and two secretaries, the staff includes an art therapist, a physiotherapist, three cooks, 3 logistics assistants and a team of volunteers. Finally, the staff of each inpatient palliative care unit is made up of the following profiles: doctor (1.5), coordinator (1), psychologist (1), nurses (9), care assistants (9), plus, common to both units, an art-therapist, a physiotherapist, a therapist delivering psychomotricity activities, an osteopath, and a socio-aesthetician.

Volunteers work in the units and in the day centre. They are recruited based on an interview, after submitting a letter of application to the volunteer coordination group. There are around sixty volunteers forming an integral part of the multidisciplinary team. Those who join the units take part in daily communications. All the volunteers also take part in a monthly discussion group and some training courses. They work in pairs every day of the week, from 9.30am to 8pm, and are responsible for a variety of tasks: accompanying residents to consultations, cultural and recreational outings, helping with meals, being present and listening to residents and their families, accompanying, participating in, and supporting artistic workshops, help with cooking, gardening, and DIY. They provide support to residents and their families and contribute to the life through their attentive and discreet presence, opening a different space for communication, a 'non-medical' viewpoint, outside of care. They also provide human support to the team, but they do not replace a professional. Volunteers enhance the daily lives of residents, families, the team, and the environment. They share the values of *La Maison* in the same way as the salaried team. Staff and volunteers work together to build a different way of being and living with residents.

5.4.6 Quality of care at the hospice 'La Maison'

'*La Maison*' has based his approach on a culture of comprehensive care. Staff works in a spirit of caring, attention and respect for autonomy to constantly improve the resident's quality of life and the support of those around them. They consider the relative needs of the patient's state of health and their physical, psychological, and social dependency.
From the outset, the establishment's management has developed a quality policy based on the fundamental criteria of cohesion and continuity of care. This policy is based on a quality improvement and risk management programme, which is reviewed annually. The quality unit coordinates the quality policy. It liaises with the HAS to monitor the certification process, as well as with the ARS, for the Pharmaceutical Good Use Contract.

5.4.7 Referrals, multidisciplinary consultation, data sharing and integrated care at the hospice 'La Maison'

The territorial outreach palliative care team establishes partnership with the palliative care network and other palliative care units in the department of *Bouches- du-Rhône*. The two inpatient PC units work closely with each patient's referring hospital department to ensure continuity of treatment.

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